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ABSTRACT

This examination of the use of aversive techniques as a form of "therapy" for people with mental handicaps includes 12 articles by specialists who argue that the use of aversive procedures is socially, ethically, legally, and scientifically untenable as well as 3 ancedotal case studies by a patient advocate and 2 personal accounts by persons who have suffered from aversive therapies, one of them a patient and the other a parent. The 12 articles have the following titles and authors: "Aversive Conditioning: Necessity or Failure?" (Tim Stainton); "The Use of Aversives: One Psychologist's Viewpoint" (Carole Sinclair); "Redefining the Problem: An Alternative View of Difficult Behavior" (Douglas Logan); "My Sister Kelly" (Mary Collins); "The Efficacy of Behaviour Modification Techniques for Persons Labelled Mentally Handicapped" (Bill Downer); "Aversive Therapy" (Dot Ewen); "This May Hurt a Bit" (Orville Endicott); "'The Therapy of Despair': A Family Medicine Perspective" (Yves Talbot); "Legal Advocacy and the Use of Aversives" (Brian Weagant and Dorothy Griffiths); "Aversives: Differential 'Treatment' for People with a Mental Handicap" (S. Dulcie McCallum); "Equality Rights and Aversive Therapy" (Catherine Frazee); "A Self-Advocate's Perspective" (Pat Worth). The personal accounts are: "Something I Would Like To Forget," by Peter Park, and "Speaking as a Parent," by Margaret Price. The three case studies, by Jill Leach, each concern an individual in successful transition from a punitive institutional environment to "living in the community." (DB)

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PERSPECTIVES ON BEHAVIOUR MANAGEMENT

THE G. ALLAN ROEHER INSTITUTE

THE LANGUAGE OF PAIN:

Perspectives on Behaviour Management

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Perspectives on Behaviour Management

The G. Allan Roeher Institute

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The G. Allan Roeher Institute
York University, Kinsmen Building, 4700 Keele Street
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Institute Director: Marcia H. Rioux
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Canada's National Institute for the Study of Public Policy Affecting Persons with an Intellectual Impairment

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Downsview, ON M3J 1P3 (416) 661-9611

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Some of the names used in this collection are fictitious.

Introduction

Marcia H. Rioux

What is the language of pain? It is a metaphor for the frequent forms of interaction between people who communicate in a way that our society does not understand and others who care and decide for these people. For some, it is a language that expresses desperation, for others, it is the expression of control and force. Above all, it is a language that expresses pain.

This collection of articles looks at how aversive techniques are used as a form of "therapy" for people with mental handicaps who present what are known as "challenging behaviours." The use of this kind of therapy to control and modify people's behaviours is not new. However, many people have become increasingly aware that such approaches to behaviour modification may at best be ineffective and at worst destructive. Many argue that aversive techniques can and do have an important impact on the emotional, physical and intellectual well-being of those subjected to them.

The continued use of aversives has finally drawn out professional groups, advocates for people with a mental handicap, self-advocates and the public at large to think carefully about the consequences of such treatment. Various advocacy groups have sponsored symposia on the issue. The press and other media have devoted space and air time to it. Government and voluntary-sector task forces have been established to study it and make recommendations about it. Scholarly works decrying the use of aversives and presenting alternatives are beginning to find their way onto the market as an alternative to the flood of literature that already saturates the field in defense of punitive approaches to behaviour modification.

Lately, attention has been particularly fixed on contingent shock treatment, although this is only one strategy in a range of "therapies" now being used on people who have a handicap and who are considered to have severe problem behaviours. Generally rationalized as a "last resort," contingent shock is said to be reserved for individuals whose behaviour is so "severe," self-injurious or aggressive that no other technique for controlling those behaviours will work.

Unfortunately, there is little concrete evidence that tells us one way or another how widely aversives are currently being used on Canadian citizens who have a mental handicap. But there is a climate of acquiescence that leads us to suspect that these techniques are being used more widely than what the limited evidence would indicate. For instance, several literature searches have shown that the overwhelming bulk of research into how to control challenging behaviours has been devoted to punitive control procedures. Governments, private foundations and other funding bodies have in turn been slow to support research into the alternatives to punishment. Because front line support staff look to this unevenly weighted body of research for their cues on how to manage challenging behaviours, it is a reasonable assumption that aversive techniques are being quite widely used.

Accordingly, the use of aversives is forcing many to look more critically at what society means by and condones as "success." Is it simply the accomplishment of a task that one has set out to do, regardless of the nature of the task; or is it to be defined in terms of the quality of life and well-being of the people whose bodies and psyches are at stake? If we go along with the first definition, any means can be justified to accomplish a desired outcome. The use of aversives on people with undesirable behaviours, in this definition, is as justifiable as the political intimidation of the urban poor in a developing country or the internment of racial minorities. These are all, according to a certain kind of thinking, apparently "successful" ways of reducing an unwanted set of socially problematic behaviours. If, however, we opt for the second definition of success, we are brought face to face with some limitations that must regulate our actions. In this instance, success implies an outcome and ways of achieving it that are in keeping with the human dignity and well-being not only of each individual, but necessarily of society as a whole.

The use of aversives also raises questions about the place of knowledge in our society, and about which kinds of knowledge deserve to be most highly valued. Increasingly, "real knowledge" is coming to be associated with that kind of scientific know-how that enables society to manipulate nature, to control the consumer and to organize productive processes. To win credibility, teams of experts will use scientific charts, graphs, tables, profit and loss projections and impressive terminologies to prove a point. That whole areas of life, such as self-esteem, human relationships, self-acceptance, neighbourhood and the sense of inner well-being, cannot be reduced to scientific quantification and measurement means that some topics are not taken as seriously as others. They are increasingly left out of public discussion. As a result, it has become perilously easy for society to believe that all that really needs to be known about those who present challenging behaviours is how many times an undesirable behaviour occurs, given that certain stimuli are introduced or removed, and how much it costs to maintain control.

The use of aversives also leads many to question the degree to which social services are drifting away from values such as simple respect for individuals and their birthright to liberty, humane treatment and reasonable support. Increasingly, people are beginning to wonder what happens over time to the values, sensitivities and judgement of those who exercise this naked force in our social service system. More are beginning to focus on how people are being victimized and on what might be happening to the professional "climate of opinion" that allows victimization to happen.

The social implications of using aversives raise many ethical problems as well. At a very general level, there is a need to clarify and to impress upon policy makers the point at which an action ceases to be an ethical good, regardless of its efficacy. We must decide whether actions that are ethically unacceptable are ever permissible, and if so, under what circumstances. In other words, where should society draw the line between what it knows is expedient, on the one hand, and what it believes is just, on the other?

On a more specific level, the use of aversives raises disturbing ethical questions about the nature of treatment. It seems to be extremely unclear at what point therapy and cruel and unusual treatment part company. Aversive therapy is arguably in a class of its own. It aims directly to produce pain in an individual, and from the individual's experience of acute pain flow all of the treatment's supposed "therapeutic" merits, namely, the cessation of an unwanted behaviour. This is quite different from other types of therapy. While "legitimate" therapies and procedures (e.g., surgery or physical rehabilitation) may be painful, the therapist does not set out deliberately to inflict pain during treatment. In fact, therapists are under a considerable ethical obligation to keep the individual's discomfort to a minimum, especially during extreme therapeutic procedures. If this humane standard of minimizing discomfort were to be applied to aversive treatment, all the supposed value of the treatment would be cancelled out. Can it justly be ranked, therefore, among the legitimate therapies?

Also ethically suspect is the notion that it is permissible to attempt to control someone's challenging behaviours through aversives when serious attempts are not being made to understand and address the causes that may be giving rise to those behaviours in the first place. For instance, people who exhibit challenging behaviours typically do so in environments where they are subject to continuous management and control, where they are deprived of ordinary human interactions and where they have few opportunities to experience life in the community in ways that others do. It is scientifically imprudent and against common sense to assume that the individual's challenging behaviours have no relation to this controlling environment, to the techniques of control or to the people who are using those techniques. An analogy would have us trying to understand the sometimes disturbing actions of blacks in South Africa outside of the socio-political context in which they occur. Consideration of environmental factors, such as the usage of control and power, is frequently left out of the analysis of the behaviour of the person who has a mental handicap. In the absence of knowledge about where the real problem lies, it is ethically questionable to proceed with treatment that is predicated on the individual being the principal source of the problem.

Likewise, it is not uncommon to hear stories about how, after a period of punitive behaviour management, the discovery was made that a simple physical disturbance like an ulcer or a sinus problem was at the root of the individual's challenging behaviour. Such discoveries after the fact will sometimes include a belated recognition that the only expressive language through which the individual knew how to communicate the discomfort was vehement gesturing and loud vocalization. In other words, the challenging behaviour was not so challenging after all. A superficial approach to the behaviour will not take these sorts of causes into account. All too quickly the outbursts are seen as aggressive, self-destructive and undesirable, behaviours fit to be terminated by behavioural technology. Needless to say, the application of aversive procedures is ethically indefensible in situations like this. They are clearly inappropriate means for obtaining the desired end, and skilled medical treatment would make much more sense, both ethically and clinically.

Aversives also raise more general questions about society's ethical obligations to the individual citizen. What, for example, are society's obligations to ensure that forms of "care" other than behaviour management and punishment are made available in meaningful ways to individuals who have a handicap and who need service or support? Too often, society's response is to point the individual in the direction of services that may be humane but that are underfunded and overutilized. Then again, the individual may be referred to a service that is simply inaccessible because of location or restrictive eligibility criteria that rule the individual out from receiving it. After all these "alternatives" are tried, the individual is introduced to the world of punishment. In these situations, society stands on a very weak ethical footing when it calls aversive treatments the "last resort."

Naturally, social and ethical questions concerning the nature of treatment have parallels in the legal sphere. Are aversive treatments real treatments (i.e., therapies) in the legal sense, or are they cruel and unusual treatments that can be equated to cruel and unusual punishment? If they are not legitimate treatments in the legal sense of therapy, then they ought not be used. If they are cruel, the individual has a constitutional right not to be subjected to them. Furthermore, if they are to be considered mere punishment (i.e., neither cruel nor unusual), why are they not more widely practised on people who do not have mental handicaps, and where is the criminal activity and due process of law that justifies their use on those who *do* have mental handicaps?

This, of course, raises the question of consent. Those to whom aversive treatments are applied are generally considered legally incapable of consenting to the treatment. Consent is given by proxy in such cases. But as the case of *Eve* made clear, proxy consent to intrusive procedures like sterilization cannot be acted on under Canadian law. Accordingly, proxy consent to intrusive procedures like aversive treatments may not be legally justifiable.

From another angle, the state punishes a lawbreaker to make him or her comply with the legal norms of society. The more clearly it can be shown that the law breaker *intended* to violate the law and the more serious the crime committed, the more harsh will be the punishment meted out. The less clearly it can be shown that the law breaker meant to deviate from the law and the less serious the offense, the more lenient the punishment. However, in the case of a person with a mental handicap, it is often argued to be impossible to elicit from the individual a legally meaningful sign of his or her *consent* to aversive treatment for challenging behaviours. How possible is it, therefore, to determine with any legal clarity what his or her *intent* might be in presenting a particular set of challenging behaviours? Are we entitled to act as we would if we presumed the individual's criminal guilt. Given that punitive forms of behaviour control are usually invoked where criminal activity is not at issue in the first place, their legal legitimacy as punishment for the purpose of eliciting compliance is all the more seriously in question.

Let us suppose for a moment that the consent to these forms of treatment can be elicited from the individual or that the proxy's consent is to be considered valid. There is still the requirement that the consent be informed. If, however, you are not told that there are effective therapies other than aversives or if you are led to believe that your only real choice is between no support, on the one hand, and aversives, on the other, can it really be said that your consent to aversives is informed? Just how informed the consent can be is also at issue when those who inform others about the procedures are those who have a vested interest in using and promoting them.

It also needs to be made clear what constitutes self-injurious or aggressive behaviour that is sufficiently "severe" to warrant the legal application of aversive procedures. There are at present no clear legal criteria that can help us in this area. In the absence of such criteria, there is a serious temptation for caregivers and others to regard behaviours that could simply be seen as unruly, non-compliant, maladaptive or undesirable as "severe enough." Too often, it is murky guess work like this that determines when it is appropriate to use aversives.

If, on the other hand, more stringent legal criteria were developed to help identify the conditions under which aversives become legally acceptable, it would follow that aversives could be legally used on people who do not have mental handicaps but who satisfy those conditions. This, however, is an outcome that few jurists would likely accept.

Aversives have also helped to make more apparent the legal confusion that surrounds the custodial care of Canadians who have mental handicaps. It is not at all clear and is becoming less so all the time to what extent, and in what ways, service providers in the community are legally entitled to exercise a custodial and restrictive role concerning citizens who have mental handicaps. If service providers are not exercising formally granted custodial and restrictive functions under the Criminal Code or under the various mental incompetency, mental health and community care acts, in what legal framework is the use of restraints and other punitive treatments justified?

The need to control the administration of aversive therapy is increasingly accepted to be a legal issue. The basic line of argument in favour of control maintains that if you carefully outline the conditions under which and the manner in which aversives can be used, you reduce the probability of abuse. However, if a more appropriate premise is that aversives are not legitimate on ethical and legal grounds, then it follows that restricting their use through controls merely lends them a legitimacy they do not merit.

The social, ethical and legal implications of aversive procedures become all the more glaring in light of the purely scientific problems that attend these procedures. It is important to stress, however, that even if the scientific issues were to be resolved, the procedures would be unacceptable on other grounds.

As it turns out, however, even the scientific underpinnings of aversives are shaky. Very little research has been done, for instance, into the long-term side effects (psychological and physical) of the treatment, so it is impossible at this time to substantiate any claims in favour of its long-term therapeutic benefits. Common sense, however, suggests that there may very well be unfavourable long-term effects. At the same time, the ethical and legal issues attending research into this issue are so serious that the concrete application and research of aversive procedures to prove or disprove their efficacy should be suspended altogether.

Another scientific problem is that those who have conducted research in support of aversives have typically not investigated the causes of the challenging behaviours that the treatment aims to remedy. Again, conclusions about the therapeutic merits of the procedures are at the very best as limited as are conclusions about the use of psycho-active drugs. These drugs do, in some circumstances, seem to alter moods and to help modify behaviours. But their long-term effects can be extremely troubling, as can their interplay with other synthetic substances, diet and environmental factors. More to the point, whether they have any meaningful relation at all to non-biological factors that evoke the undesirable moods and behaviours is seriously in doubt.

The bias of research and of the funding of research has also played a part in preventing a thorough and systematic investigation of non-aversive approaches to addressing challenging behaviours. Detailed scientific analyses and comparisons of aversives to non-aversive approaches cannot, therefore, be made on scientific grounds alone. It has consequently not been possible to make conclusions within a rigorously scientific framework about the supposed merits of aversive procedures in relation to other approaches.

Similarly, very little published material exists about when and under what conditions aversives have *not* proven effective in dealing with challenging behaviours. Consequently, making scientific generalizations in support of the presumed efficacy of these procedures is at best hazardous. Again, this information gap seems due in part to the biases both of researchers and of the criteria by which fiscal allocations are made for research.

Furthermore, the conditions under which aversives have been researched and applied have been highly controlled. This makes it very difficult if not impossible to make generalizations on the basis of that research about the long-term effectiveness of treatment in relatively non-controlled conditions.

A parallel problem is that the so-called efficacy of aversive treatments is assessed in environments where the "therapists" are readily able to re-apply a range of technologies and resources that have been designed to elicit the individual's compliance. The existing research does not look at what part is played by the continual, latent threat of punishment inspired by those environments. This oversight does much to cancel out the merit of any generalizations about the efficacy of the treatment. Is compliance within such environments the real aim of treatment? Can treatment be classed as effective when it elicits compliance in relation to such a punitive milieu?

It is only in such an enclosed world of control, in which the language of pain is the language of everyday life, that "science" is free to busy itself matter-of-factly with noting the statistical correlations between the introduction of aversive stimulants and the occurrence of unwanted behaviours. In such a world, science is not obliged to look at the terror that the individual feels, nor can it measure the degree to which this terror affects his or her behaviour. It cannot, therefore, predict with any certainty what the individual's behaviours will be should he or she be fortunate enough to experience life again outside of the regime of terror, where the language of pain is less frequently used.

This book is intended to provide Canadians with the opportunity to speak out on this important issue. The work includes the views of a number of specialists (doctors, lawyers, psychologists) who argue that the use of aversive procedures to alter human behaviour is not only socially, ethically, legally and scientifically untenable; it is unjust. But the most important contribution to this publication is made by those who have known the language of pain. This book enables them and their families to describe their experiences and to voice their thoughts, concerns, fears and hopes.

The Canadian Association for Community Living's Stand on the Use of Aversive Techniques

The Canadian Association for Community Living (CACL) unanimously passed a resolution at its 1987 Annual General Meeting in Halifax, Nova Scotia advocating the use of non-intrusive methods in interactions with persons with a mental handicap. The resolution stated

> That CACL resources and expertise be dedicated to the development, implementation, evaluation, dissemination and advocacy of positive non-intrusive supports to persons experiencing severe behaviour difficulties appropriate for use in integrated environments; and
>
> That aversive conditioning which involves any or all of the following characteristics be eliminated:
>
> i) systematic infliction of physical pain, physical and/or emotional trauma;
>
> ii) dehumanization of the individual;
>
> iii) techniques inappropriate for the individual's age;

iv) treatment which is out of proportion to the target behaviour;

v) procedures which are normally unacceptable for non-handicapped individuals, and, in particular but not limited to, social degradation, social isolation, verbal abuse, electric shock, mechanical restraints, water or lemon juice spray and noxious stimulation (taste, smell or noise), and

Further that the Federal Minister of Justice, the College of Physicians and Surgeons of Canada and the Canadian Psychological Association be informed of CACL's position on this issue.

The Canadian Association for Community Living is Canada's national advocacy association for people with mental handicaps. It has been in existence since 1958 and represents a vast network of people with handicaps, professionals, volunteers and decision makers, all of whom believe that all persons with mental handicaps have a right to live rich lives as full participating members of their communities.

Something I Would Like to Forget

Peter Park

Okay, some of you will say, "What does he know about aversive treatment?" I am writing this from a different slant. The things that I describe here actually happened to me. I have to think back. It is in a way something that I would like to forget.

In 1960, I entered the institution to have my epileptic seizures controlled. After eighteen years, they still hadn't succeeded in controlling them. "Oh," you say, "Why so long?" Well, I originally went into the institution to have my seizures brought under control with medication. There were two doctors who admitted me. After three days, one doctor died. I said to myself: "Old age, likely." About six days later, the second doctor passed on, and I became a name and a number on a piece of paper that was conveniently lost for eighteen years. I was given Dilantin and phenobarb, plus other drugs. We were used as guinea pigs to try out new drugs that aren't normally available through the CPA (Canadian Pharmaceutical Association) or in Merck manuals. Okay, I said that I was institutionalized for eighteen years. I am estimating that I was in a lock-up for nine of eighteen years. A lock-up is a form of aversive therapy. I was held by a staff member while another staff squirted lemon juice in my face.

1.

Aversive Conditioning: Necessity or Failure?

Tim Stainton

The use of aversive conditioning techniques to modify the behaviour of people with a mental handicap is one of the most controversial and emotionally charged issues facing professionals, families and individuals alike. On the surface, the issue appears to be a clear and simple question of what is just and proper treatment. As one looks deeper into the question, however, the complexities become evident and the issue becomes clouded in a plethora of questions. What are the alternatives? What powers and privileges do the professionals hold? Is there a "right to treatment" and who oversees it? What is an aversive? This article will explore some of the reasons, stated and unstated, with which we are confronted concerning this issue and the alternatives.

What is Aversive Conditioning?

The question of what constitutes aversive conditioning is seemingly simple but it lacks any specific and universally accepted definition. Definitions range from narrow ones, which refer exclusively to procedures involving physical punishment, to broadly based definitions, which include anything the individual may perceive as unpleasant or to which he or she may be averse. The following definition does not attempt to be conclusive but provides a working definition from which to understand the overall issue:

An aversive procedure or intervention is any procedure that is designed to modify the behaviour of an individual through the intentional application of a physically or emotionally painful stimulus.

It is important to clarify that these are planned interventions designed to change a specific behaviour or behaviours or, in rare cases, encourage the development of new behaviours. It does not include the random use of punishment such as spanking or sending someone to their room. These may be equally abhorrent but they are not aversive conditioning techniques.

In a comprehensive study on the use of aversive conditioning prepared for The Association for Persons with Severe Handicaps (TASH), a review of sixty-one journal articles identified the following aversive stimuli commonly employed:

- electric shock
- vinegar or lemon juice sprayed in mouth
- physical restraint
- mechanical restraint
- slapping
- immersion in cold water
- ammonia capsule under nose
- shaving cream into mouth
- white noise at 90 db
- water sprayed in face
- pinching
- teeth/gums brushed with oral antiseptic
- forced body movements
- ice on cheeks
- contingent exercise
- verbal reprimands[1]

While disturbing in itself, this list raises even more questions when compared to a list of common means of torture identified and condemned by Amnesty International:

- electric shock
- verbal abuse
- plunged into cold water
- strenuous physical exercise
- high pressure water squirted into mouth[2]

What is interesting about this similarity is the general reaction each receives when presented in their separate context. While there is general revulsion and widespread outcry at the latter, these remarkably similar procedures, when used as "treatment" for persons identified as mentally handicapped, are regularly condoned and supported by our governments and society in general. It is this question of why we react, or do not react to these procedures that needs to be explored to fully understand the use, justification and pervasiveness of aversive procedures.

Why, Where and on Whom are Aversive Procedures Used?

The literature reports the use of aversive procedures for a wide variety of behaviours considered to be maladaptive or inappropriate. The most highly aversive methods are commonly used for the "treatment" of severe self-injurious or aggressive behaviour. There have been published reports on the use of aversives for such inconsequential behaviours as grabbing tokens, getting out of a seat at inappropriate times and whining. The focus here is on the use of aversives for the first two categories of behaviour: self-injury and aggression.

The behaviours can be severe and, in some cases, life-threatening to the individuals. People labelled severely or profoundly mentally handicapped constitute the majority of those subjected to aversive conditioning.[3] In addition, there is a high incidence of persons with allied sensory or communication impairments (i.e., blindness, deafness, autism) who are subjected to these "treatments."[4] While they have been used on people of all ages, the most prevalent use seems to be with children and young adults between the ages of seven and twenty-one years of age.[5]

The use of highly aversive procedures occurs primarily in institutional settings. There is, however, widespread use in educational and community settings.[6]

The use of aversive measures on people living in institutional settings raises a disturbing scenario aptly articulated in the following citation from Guess and Turnbull:

> It is a horrible paradox that persons with the most disabling conditions regularly have been placed in environments that are the most likely to produce or enhance the types of

> deviant behaviours that subsequently activate the behavioural technology and research designed to reduce or eliminate those same behaviours.[7]

While the horrors of certain institutional environments are well documented, and it is true that the majority of highly aversive procedures are employed in institutional settings, this does not imply that the community is without fault or responsibility. The first and most obvious criticism is the fact that all people in institutional settings came from the community at one time. While there is ample information on why and how this has occurred, the simple fact remains that the communities allow their members to be segregated from them, either for long periods, or intermittently for "treatment."

The director of an institutional program using aversives pointed out that many of his "clients" come to him at the request of community agencies. Those same agencies often refuse to accept the individuals back when "treatment" is complete.

What is more distressing is the increasing use of aversives in community settings.While time-out rooms have long been used in many community residential and educational programs, there is an increased use of mechanical restraint programs and other more aversive techniques.

There are several reasons for this. Most obviously the deinstitutionalization thrust has meant that communities are less and less able to remove those people perceived to be "more difficult" to segregated institutional settings. When faced with a new type of behaviour, there is a tendency to turn to the institutional settings for help since they are the ones who are perceived to have the expertise in dealing with the behaviours. In effect, this process transfers the institutional norms to the community, defeating much of the potential benefit of community living.

Community services also have a long tradition of segregating by perceived problem in much the same manner as the institutions have historically done. This results in large group homes for people with challenging behaviours that generate the same problems described in the previous citation from Guess and Turnbull, and increasingly the same solutions.

Does Aversive Conditioning Work?

The question of whether aversive conditioning procedures actually work may seem irrelevant to some who feel their use is unacceptable under any circumstance. But it is an important question helping to understand why aversive procedures continue to be used despite the legal and ethical issues raised by their use.[8]

In the TASH review mentioned above, the following conclusions were reached:

1. Aversive measures can reduce a wide range of behaviour problems. The authors qualify this by noting that research that shows weak or negative results is seldom published.
2. Effects appear to be durable for short periods. However, most of the literature fails to provide follow-up data. When it does, it is usually for periods of twelve months or less and follow-up conditions are poorly described.
3. The majority of the studies fail as well to provide data on the generalization of effects. Of those that did report, over half reported some generalization, but usually measured in a limited number of settings.
4. Adequate experimental designs were present in only a small number of studies.[9]

Another study with a mandate to review the literature on state-of-the-art research in both behavioural and non-behavioural approaches to the treatment of self-injury and aggression among people with developmental disabilities made similar findings. This review of over 250 articles reached some interesting conclusions on the prevalence of punishment techniques and the lack of investigation into non-aversive approaches:

1. Behavioural treatments have frequently been successful in dealing with self-injurious and aggressive behaviour in persons with a mental handicap.
2. The behavioural treatments used tend to involve punishment techniques.
3. There is no conclusive evidence in the literature supporting the general superiority of any one technique, aversive or non-aversive.
4. There is no conclusive evidence supporting the superiority of shock over any other treatment.

5. The small body of literature on exclusively non-aversive approaches would seem to indicate an apparent preference for aversive techniques over non-aversive approaches.
6. There is ample evidence that there is a fairly large body of literature on non-aversive approaches that might be effective but as yet have not been given sufficient exploration.
7. What evidence does exist would seem to indicate that extra effort should be made to give these non-aversive approaches more thorough consideration when treating difficult behaviours.[10]

From both these reviews it is clear that there is no definitive evidence indicating that aversive methods are consistently successful, that they have sustained effects, or that they are generalizable to other settings. Furthermore, the second review indicates an apparent preference for the use of aversives over non-aversive techniques. This raises the question: why are these methods so readily applied when their effectiveness is far from assured?

Why Aversive Methods Have Been and Continue To Be Used

There is no singular or simple reason why, in the face of questionable scientific support and serious moral, legal and ethical concerns, aversive methods continue to be widely used.

The Efficacy Argument

The main justification cited for the use of aversives is their perceived efficacy in dealing with severe behaviour difficulties. When examined more closely, this argument does not present the formidable weight of "scientific" fact that the exponents of aversives would have us believe. The two studies above only deal with the published literature, which is likely to report only successful findings. In practice, one can assume an even lesser degree of success. This assumption is borne out by the current trend among those who advocate aversive procedures to develop "centres of excellence." This suggests that current levels of practice are far from congruent with even the current research findings.[11]

This pattern can also be seen in the province of Ontario, the only Canadian province that allows the use of electric shock. While the literature suggests that electric shock is effective over the short term, numerous cases of long-term use exist. One woman has been on the shock program for twelve years. Another woman was on for two-and-a-half years until her parents took her home. There is also indication of the need for "successful clients" to return regularly for follow-up "treatments." In light of the questionable literature, and the even more questionable practice, the efficacy argument cannot support the continued use of aversive methods.

The Last Resort Argument

Many argue that highly aversive measures are only used when all other alternatives have failed. This is usually presented under the doctrine of the least restrictive/intrusive alternative so that a hierarchy of procedures is attempted before using such highly aversive methods as shock. In other words, the patient suffers a long and painful process of "treatments" leading ultimately to physical punishment, or, in some cases, submission. The problem with this argument is the definition of "all other treatment methods." This is usually limited to other forms of aversive behavioural techniques and pharmacological interventions directed solely at the "problem behaviour." The following citation from a research report on the use of shock on a young man illustrates this point:

> Prior to his present placement, Jack had lived in five different institutions for periods ranging from six months to four years. His previous records indicated that a variety of procedures had been unsuccessfully used to treat his aggression including water misting, exclusionary time-out, medications, over-correction, differential reinforcement of other behaviours (DRO), differential reinforcement of incompatible behaviours (DRI), required relaxation, contingent exercise, and contingent restraint ... token economy program plus exclusionary time-out ... reinforcement for appropriate social behaviour, contingent aromatic ammonia ... continuous wrist restraint and four-way mechanical restraint.[12]

The preference for the use of both behavioural and aversive methods was also identified in the Riznek review. Rarely are non-behavioural or even non-aversive methods considered in the search for alternatives. Even rarer is a comprehensive attempt to deal with the underlying cause of the behaviours through individualized planning and support development. The last resort argument is not sufficient to support the use of aversives.

The Right to Treatment, Informed Consent and Procedural Controls

The right to treatment argument has become more common in the face of rights-based advocacy against the use of aversive procedures. This means that the person has the right to all reasonably available and effective treatments. The obvious first problem is that aversives have not been proven to be effective with sufficient clarity. Second, the "right" to treatment does not abrogate an individual's right to be free from cruel or unusual punishment, their right to personal autonomy, and their protection under the law from physical assault. Nor can this justify the use of procedures that do not meet reasonable standards of ethical practice. The right to treatment argument is not sufficiently strong to justify the use of highly aversive methods.[13]

Informed consent is central to the right to treatment argument and other current justifications for aversive procedures. In the majority of cases, the consent to "treatment" is not given by the person who will be the recipient of the treatment. Age and/or the perceived competence of the person involved accounts for this. Consent is usually given by a parent or guardian, often regardless of whether there has been due process in determining competence. This immediately weakens the strength of the consent and calls into question its validity from both a moral and legal standpoint. The *Eve* decision in Canada effectively removed the right of a parent or guardian to consent to non-therapeutic sterilization.[14] The principle inherent in this decision seriously questions the validity of substitute consent in relation to the use of aversive procedures.

The issue of what constitutes or purports to constitute consent in relation to aversive procedures arises in the case of Jack. His consent form, which was developed by those implementing the shock program, is described by its authors to include the following:

> The results of previous treatments; (e) a description of possible treatment alternatives with prognostic details regarding their anticipated success (e.g., further chemical restraint might have been attempted, but due to past failures and potential side effects, it was extremely unlikely to produce any desirable results); (f) a review of the literature

> reporting the successful treatment of aggression with shock ... (g) a justification for the use of shock based on Jack's right to effective treatment and the poor prognosis if a potentially effective treatment was not tried ... (m) the anticipated treatment results; and (n) an extensive reference list on the right to treatment and the use of shock to treat maladaptive behaviour.

The authors go on to say that the consent form played a very important role by detailing the proposed treatment and demonstrating parental and administrative support.[15]

The consent form was clearly a mechanism for "selling" the program to the family. The inclusion of "extensive material" on right to treatment is irrelevant to the decision for treatment and is clearly intended as a coercive element. The description of an extremely negative alternative coupled with the proposed implementers' description of potentially beneficial effects of shock is also coercive and again is clearly intended to influence the decision of the family. Without independent advice and a truly independent assessment of the program and the alternatives, the consent cannot be construed as truly informed.

The following story based on an interview with the mother of a woman subjected to shock illusrates a common problem with consent:

"At the time they put Toby on this program (contingent shock), I was informed by Dr. X that it was either that or a padded cell. There was nothing else to do, I was given one choice or another." After two-and-a-half years on the shock program, the mother noticed no positive change in her daughter and she decided to bring her home without the shock program or any other kind of supports.

Procedural hurdles such as human rights reviews and professional reviews are often employed as a final mechanism to support the use of highly aversive methods. While ostensibly a good mechanism, these processes have not seriously limited the use of highly aversive measures. Human rights reviews are questionable since their mere existence suggests that the human rights they are reviewing are contingent and may not apply to certain individuals based on professional evaluation of their behaviour. They become negative when they appear to sanction aversive procedures and thereby add validity to their use.

Professional reviews are often *pro forma* and are usually completed by other behavioural professionals conversant in and sympathetic to the use of aversive techniques. This prescreening of ideas, input and disciplines renders them all but useless except perhaps in cases of flagrant abuse or misapplication from a theoretical standpoint. Again their chief purpose is often to legitimize the use of the procedure.

None of the standard justifications for the use of aversive conditioning provides a clear enough *raison d'être* to account for the widespread and consistent use of aversive procedures.Training, anxiety and convenience may well account for their past and continued use.

Training, Anxiety and Convenience

Perhaps the most obvious reason for the widespread use of aversive measures is the training we offer most workers in the field. The positive impact of behavioural training techniques on our ability to teach people with exceptional support needs cannot be denied. As such, it has increasingly formed a large part of our training and educational programs for current and future staff. Behavioural science also allows researchers in academic and clinical settings the kinds of experimental design and rigorous analysis of "hard data" often required in such settings. These same settings and researchers also provide the majority of the training and educational programs. Thus, in our zeal to be "scientific," we may overemphasize the technology that is most readily amenable to quantification. An example from a student placement project of a community college program for developmental service workers is useful here.

A summer program for children from the local institution was organized that involved integrating them into the regular summer activities organized by the local parks and recreation department. Each of the students was responsible for helping one of the children participate in the program as fully as possible. Activities included playground, trips to parks and zoos, games, etc. It was not intended to be a teaching program, but purely a recreation and leisure program. The children fit in well and were soon having a great time with their friends from the community. As organizers, we considered the project a great success.

At the evaluation, however, one of the students and the instructor felt the whole thing was an utter failure because they "did not have one opportunity to task-analyze an activity or develop a program plan." Clearly something was seriously amiss with the college training if they failed to see the integration of children, who had spent the bulk of their lives in institutions, into regular recreational activities as anything but a tremendous success. Unfortunately the emphasis on technical behavioural analysis had taught them to assess success not in human terms, but in terms of technical results.

The "spread effect" outlined in the TASH monograph also applies here. This refers to the process where an initial success (i.e., the suppression of the maladaptive behaviour), even for a short time, reinforces the worker. This positive reinforcement encourages the worker to resort to aversive measures more often and in less severe situations. This results in a gradual spreading of the use of aversives from what may have been an initial, limited use.[16]

This effect is likely to be magnified in situations where staff resources are severely limited. One of the great attractions of aversive technologies is their relative ease of use and their perceived time-limited nature. Human service organizations frequently suffer from a lack of resources. Thus, the temptation to apply a procedure that does not require a great investment of time in the development of a meaningful relationship or highly individualized supports is great, particularly if the procedure promises to be time-limited with relatively immediate success.

Finally there is the anxiety of staff, family and friends when faced with extreme behaviours that are often frightening to witness. As Lovaas has noted: "therapists ... may select aversives because of their own 'anxiety' and thereby become aggressive themselves."[17] Unfortunately, our instinct often tells us to fight fire with fire, regardless of whether that will cool the flames or ignite them.

Behaviourism as Ideology

One of the more subtle but perhaps most pervasive reasons for the widespread use of aversive techniques has to do with behaviourism itself. As we have noted, applied behaviour analysis has had a profound and generally positive effect on our ability to teach individuals with a mental handicap. But there are some fundamental problems when behaviourism is applied exclusively or without regard for the broader social context. McGee et al. raise this point clearly: "there are two basic problems in the practice of behaviourism. One problem is that the traditional application of these principles is based on a unilateral, rather than an interactional, approach to change. A substantive flaw is that applied behavioural analysis is regarded as an all-encompassing philosophy of life."[18]

McGee and his colleagues suggest we need to look critically at our basic posture towards those we seek to support. Behaviourism, when applied as described above, leads to a state of compliance and reflects an authoritarian attitude or value system. On the other hand, a more interactional approach implies a posture of solidarity that leads to reciprocal human interaction.[19] Turnbull et al., citing the work of Haille on the nature of cruelty, state this same point more simply: "the opposite of cruelty is not kindness, but respect."[20] Behaviourism, when seen as an ideology, reflects an unequal power relationship that involves the therapist obtaining control or compliance. In this context, punishment is inevitable. Only when the tools of behaviour analysis are used in a context of mutual respect and equality can the use of punishment and force be avoided.

Devaluing and Depersonalization

The devaluing of people labelled mentally handicapped is a longstanding and pervasive fact in our society. Evidence can be seen in our past and present treatment and attitudes. No other population has been consistently segregated from the mainstream of society. Fear of the "feebleminded" has long influenced the development of a system of control that we are gradually struggling to reform. Unfortunately, this legacy of fear and devaluing continues to allow us to treat people labelled mentally handicapped or other devalued groups in our society differently than ourselves. Turnbull et al. provide a comprehensive discussion of this dual standard. They point out by way of example, that highly aversive methods are not routinely used to deal with the equally self-destructive behaviour of an alcoholic. They also review three cases from the U.S. Courts on the use of aversive behavioural interventions on psychiatric inmates, prisoners in correctional settings and people in facilities for the mentally handicapped. In all but the case involving people with a mental handicap, the judges ruled that the use of aversive conditioning techniques violated the individual's rights of consent and freedom from cruel and unusual punishment. In the case involving people with a mental handicap, it was ruled lawful if administered by a qualified mental retardation professional.[21] In Canada, there have been no legal challenges to date, and the attitudes reflected in these decisions are no less pervasive.

The question becomes one of our values and our attitude towards people identified as mentally handicapped. Without a fundamental change in attitudes, we will continue to accept the punishment of people based on a label that no more defines the person than their sex.

This process of devaluing and depersonalization is strongly evident in the literature on aversives. People are described routinely as a list of problems and diagnoses as in Jack's story — "The Successful Treatment of a Dually-Diagnosed Deaf Man's Aggression with a Program that Included Contingent Electric Shock."[22]

When presentations are made on the use of aversives, it is common to use videotapes showing people in their direst moments. To a large degree, the drama of the result is dependent on displaying the most traumatic and desperate "client" possible. This reinforces the underlying stigma that supports our dual standard and allows us to contemplate the use of means we would otherwise reject.

The terminology used to describe aversive measures also effectively allows us to depersonalize the events. The application of a cattle prod to people is variously described as "faradic stimulation," "contingent electric shock" or, in the article cited above, the instrument itself is described as "the direct stimulator."[23] The use of pseudo-scientific euphemisms allows us a psychological distance from the events, which, while obscuring the reality of the situation, allows us to distance ourselves from the responsibility of ethical choices.

This general devaluing, coupled with an over-reliance on behavioural technology to provide solutions to human problems, can lead to ignoring even the most blatant attempts to communicate very real difficulties. Rather than seeing the problem, we jump to treat the behaviour. Barry is a case in point.

Barry is a forty-year-old man who had lived in a large institution for most of his life. Over the years, he developed what were described as severe self-abusive behaviours. In Barry's case, this involved forced vomiting and prolapsing his bowel and tearing at it. This resulted in severe bleeding and eventually chronic anemia. He was "treated" with a series of programs culminating in a restraint and time-out program. When the institution closed, it was assumed Barry would be one of the few who could never live in the community and would have to be transferred to another institution. Fortunately, a community service provider offered to develop a highly individualized support system for Barry. Part of the initial settling in involved a visit to a local general practitioner for a thorough physical examination. After a series of tests, it was discovered Barry had a severe ulcer. When treated, his "behaviour problems" quickly disappeared and he continues to live a full and enjoyable life in his own home. Thus for Barry, the assumption that it was "just behaviour" and the failure to try to understand what he was trying to communicate had serious physical consequences and nearly resulted in his spending his entire life restrained in an institution.

What are the Alternatives?

Perhaps the most effective argument the proponents of aversive measures have made is the lack of alternatives. In the province of Ontario, the Minister responsible has stated he will immediately end the use of shock when a suitable alternative is available. The issue of alternatives is ultimately the most important, not only as a prerequisite for terminating the use of aversives, but more importantly to find the means of supporting people who develop severe behaviours such as self-injury.

Many proponents of the use of aversives present chemical and physical restraints as the only other alternatives for severe behaviour difficulties.They then present aversives as a humane and positive alternative. This simplification assumes that no other alternatives exist. This is the dominant belief.

One of the reasons for this belief in the lack of alternatives has, as the Riznek study pointed out, been the preference for research into aversive measures as opposed to non-aversive strategies. This is supported by Guess et al. who point out that until 1985 no comprehensive textbook on non-punitive methods of dealing with severe behaviour difficulties existed and little research is being done in the area.[24] This situation has changed dramatically in the past three years with the publication of several authoritative books and numerous articles on non-aversive means of supporting people with severe behaviour difficulties.[25]

While we are seeing an increase in literature on non-aversive strategies emerge, there remains a pervasive belief that aversives are necessary and that the alternatives offered may provide an answer for some or even most people, but for those with the most severe difficulties, aversive procedures will continue to be needed. There is, of course, no way of technically demonstrating this unless of course a means of determining absolute comparability of different individuals' behaviour could be found. The only plausible solution to this dilemma is to alter the way we perceive the problem and, by extension, the solutions.

The behavioural perspective has narrowed the perception of the problem to a set of behaviours that can be changed upon application of proper stimuli. This has led to a range of procedures that presumably can be applied universally and progressively until a sufficient stimulus is found to prompt a change in response. Recently, this view has been challenged, even within the behavioural community, by the assertion that behaviour is first and foremost communication.[26] While seemingly a rather obvious assumption, it has not, until recently, influenced the general approach to severe behavioural problems. Even this development has not eliminated the perception that a procedural solution, based on behavioural technologies, can be found. It is this emphasis on finding a "cookie cutter" solution that has limited our ability to find and demonstrate the real alternatives to aversive measures.

This consistent belief in a procedural or technical solution to the problem of severe behavioural difficulties has limited our ability to see both how our current structures encourage and sustain severe behaviour difficulties and how solutions for individuals may be found.

The Community Integration Project sponsored by the Center on Human Policy at Syracuse University conducted a nation-wide survey in the United States to identify community programs and services that were successfully supporting people with challenging behaviours to live in integrated community settings. Upon analyzing the similarities of these programs, they identified the following components as consistently present and crucial to the success of these programs:

Commitment to integration: This commitment involves a clear stance that people would not be sent back to the institution. More importantly, it reflects a commitment to the individuals and acceptance of the responsibility for finding means of supporting them in our community.

Ecological perspectives on behaviour: The quality of the individual's life both physically and emotionally was seen as paramount. Behaviours were not seen as part of the person, but rather as an attempt to communicate some difficulty the individual is experiencing in his or her environment.

Small settings: While increasingly seen as important for everyone, it is particularly important for people who require a high degree of support and who need the opportunity to develop strong relationships with others to better express their wants and needs and to be better understood.

Small agencies: This is essential to ensure that the agency remains responsive, flexible and genuinely committed to the individuals they serve. Thus, expansion is seen as less preferrable than supporting the development of new organizations.

Heterogeneous groupings: This is crucial to prevent a situation where staff find themselves managing a number of competing, often violently expressed, interests. It also allows for a more integrated and varied lifestyle by providing a greater diversity of interests and capabilities. This also prevents a situation where behaviour difficulties are transferred from one individual to another and provides an opportunity for positive role modelling.

Individualization: This is particularly important if we accept that behaviour is primarily communication. Only through a highly individualized program can the necessary degree of responsiveness to the individual be achieved. This must extend to all aspects of support, including staff selection to ensure personal compatibility.

Flexibility: This is a natural extension of individualization. Flexibility as opposed to rigid adherence to a fixed program is essential if genuine individually determined supports are to be provided on an ongoing basis.

Positive interventions: While extensively discussed previously, this is also a necessity if the above criteria are to be met. One cannot be respectful of individuals one moment and punish them the next and build a positive relationship based on equality rather than control.

Support Services: This is critical in small community settings where in-house services normally found in institutional settings are not readily available. Crisis support, consultation and respite are all essential ingredients. Ironically, the lack of these services is often used as justification for the maintenance and expansion of institution-based services rather than the development of community-based services.

Central role of the direct service provider: This is primarily a recognition that those who are with the person most and know him or her most intimately are usually the best able to interpret the person's communciation as opposed to an outside "expert on behaviour problems." This does not deny the role of others; it merely emphasizes the importance of the direct and personal knowledge of the individual. This would also apply to family, friends and advocates who again usually know the person best and whose commitment is to that person as an individual, not as a client.[27]

These components are strikingly dissimilar to the standard community services for people labelled mentally handicapped, yet they are similar to what is being described as positive support options for people with a handicap of any kind.

In a nutshell, the Syracuse findings tell us that when treated with respect and dignity, and given our autonomy, our need to rebel is eliminated. Increasingly, we are seeing people previously written off by society as being "too handicapped," "too medically fragile," or "too behaviourally difficult," living dignified and meaningful lives in our communities. New approaches to planning and support, such as service brokerage,[28] and personal futures planning,[29] all emphasize the individual's right to choice and autonomy and to be supported in ways that are dignified and respectful of both the individual and his or her personal choices, however they may be expressed.

It only makes sense that those in greatest need require the greatest effort to bring this about. They do not need something "special," merely our utmost support to achieve what we all value.

Notes

1. Doug Guess (a), Edwin Helmstetter, H. Rutherford Turnbull III, Suzanne Knowlton, *Use of Aversive Procedures with Persons who are Disabled: An Historical and Critical Review* (Seattle: The Association for Persons with Severe Handicaps, 1987), 16-17, 24.
2. Guess et al. (a), 24.
3. Guess et al. (a), 19.
4. Task Force on Research into Alternatives to the Use of Response Contingent Shock, Report of the Task Force on Research into Alternatives to the Use of Response Contingent Shock (Toronto: Ministry of Community and Social Services, 1987), 8.
5. Guess et al. (a), 22.
6. Guess et al. (a), 21.
7. Doug Guess (b) and H. Rutherford Turnbull III, "Technological Abuse or Responsibility?" *Newsletter TASH* 13:7 (July, 1987): 11.
8. H. Rutherford Turnbull III and Doug Guess, "A Model for Analyzing the Moral Aspects of Special Education and Behavioural Interventions: The Moral Aspects of Aversive Procedures," *Ethics of Dealing with Persons with Severe Handicaps* (Baltimore: Paul H. Brookes Publishing Co., 1987).
9. Guess et al. (a), 11-12.
10. Lori A. Riznek, Review of the Literature Related to Self-Injury and Aggressive Behaviour among Developmentally Handicapped Persons (prepared for the Ministry of Community and Social Services, Province of Ontario, 1987), 44.
11. Brenda K. Altmeyer, Bill J. Locke, James C. Griffin, Robert W.

20. *Wyatt v. Stickney*, 325 F. Supp. 781 (M.D. Alabama, N.D., 1971); 344 F. Supp. 373 (1972); 344 F. Supp. 387 (1972).
21. The precise right is still limited to situations involving civil commitment. Query: would the doctrine apply to "informal patients"? In Ontario, facilities can lock up patients who are admitted under some authority other than *Mental Health Act* certification. That other authority can be committeeship (pursuant to the *Mental Incompetency Act*) or common law parental rights. Although the status of the "informal patient" is technically different than that of the certified patient, the liberty restrictions are equal and in both cases the individual has been "committed" pursuant to some statutory or common law power.
22. *Eubanks v. Clarke*, D.C. Pa., 434 F. Supp. 1022.
23. *Rone v. Fireman*, D.C. Ohio, 473 F. Supp. 92.
24. See J. Parry, "Least Restrictive Alternative," *Mental and Physical Disability Law Reporter*, 9, at 314, and J. Parry, "Youngberg and Pennhurst II revisited — Part 1," *Mental and Physical Disability Law Reporter*, 10, at 154. Parry reports that one state health department has interpreted the line of cases in the United States as saying there is no constitutional need for therapeutic interventions that would enhance an individual's ability to progress.
25. *Shelton v. Tucker*, 364 U.S. 479 (1960).
26. This is consistent with other Canadian child welfare legislation. Most statutes give paramountcy to the best interests of the child but recognize the need to use the least restrictive form of intervention.
27. *Child and Family Services Act, 1984* S.O. 1984, Chapter 55.
28. *Reference re B.C. Motor Vehicle Act*, [1985] 2 S.C.R. 486, per Lamer J. at 503.

2.
The Use of Aversives: a Psychologist's Viewpoint

Carole Sinclair

> In adhering to the principle of Responsibility to Society, psychologists ... participate in the process of critical self-evaluation of the profession's place in society and about the ways the profession might be contributing to or detracting from beneficial societal functioning and changes.
>
> (Canadian Psychological Association, 1986)

The field of psychology has played a major role in the development and use of aversives. The theoretical framework has been provided by psychologists studying the learning process in human beings and animals, and psychologists were the first to systematically study the effects of aversives on learning. Therefore, it is appropriate for a psychologist to write a chapter in a book on the topic of the use of aversive therapy with persons who have a developmental handicap. It also seems appropriate to review the use of aversives from the point of view of professional ethics, inasmuch as aversives are inherently coercive, are vulnerable to abuse and have resulted in numerous guidelines for ethical and competent practice. The reflections presented will be based on personal impressions and experience and will be organized around the four ethical principles guiding the new code of ethics adopted by the Canadian Psychological Association (CPA) in 1986.

Respect for the Dignity of Persons

The first ethical principle articulated in the CPA code of ethics is Respect for the Dignity of Persons. This principle requires psychologists to view persons as ends in themselves, with a right to safeguard their own dignity and sense of "personhood," and to view science as a means to such an end. Rights to equal justice, privacy, autonomy and self-determination are seen as paramount, and individual differences related to such characteristics as age, physical and intellectual abilities, gender, etc. do not diminish those rights. Also of particular importance to the provision of services to persons with a developmental handicap is the added recognition that some persons are more vulnerable than others to having their rights ignored (e.g., children, involuntary clients, persons with a developmental handicap, women) and that psychologists have an increased responsibility to protect individual rights in relevant circumstances.

Do psychologists respect the dignity of persons in the use of aversives? On the positive side, we find that North American psychologists have responded to reported abuses of aversive methods and relevant legal decisions by playing a leading role in the development of state and provincial guidelines for their use. Such guidelines generally recommend that aversives only be used when other methods have failed and when the individual's overall well-being (or sense of "personhood") is threatened. The guidelines also often recommend the existence of expert review teams whose job it is to protect the rights of the individual with a handicap by ensuring that the application of aversives will indeed benefit the client and that all necessary consent procedures have been carried out.

On the negative side, there are still both suspected and reported abuses and insufficient consideration given to more positive ways of changing behaviour. Long-term effects of severe restraints on an individual's autonomy and self-determination have not been studied systematically, although they are sometimes reported anecdotally. Therefore, we are not sure whether long-term dignity and well-being is enhanced enough by the use of aversives to justify the short-term assaults .

Despite guidelines to the contrary, parents asked to consent to aversive procedures sometimes report that they were told there were no alternatives to the use of aversives and/or that there would be no negative side effects. However, the very fact of substitute consent for persons deemed unable to give their own consent has been seen as a problem. Consent is sometimes obtained from those who have the legal authority to do so, but who have little personal history with or knowledge of the individual and a questionable commitment to protect their rights and well-being (e.g., family members or relatives who have had no contact with the person for months or no caregiving relationship for a number of years). Although review committees are seen to provide an extra level of protection in such circumstances, they have been known on occasion to have their own biases and personal agendas (e.g., a need to protect the existence of a particular department or service). All of this suggests that adherence to guidelines does not necessarily protect the rights of the persons involved and that a psychologist cannot abdicate his/her personal responsibility to protect those rights by arguing that "everything dictated by the guidelines was carried out."

A final concern related to the principle of Respect for the Dignity of Persons is that persons with a developmental handicap form the only group of individuals in North American society who are systematically subjected to the application of aversives. Two possible exceptions include the infrequent short-term use of aversives to treat over-eating, smoking, drug-dependence, and to treat some sexual disorders in persons who can provide their own consent and discontinue treatment at any time. Psychiatric patients and prisoners sometimes display dangerous behaviours (self-injury and severe aggression) that could be treated by aversives, but it is against the law to use such techniques without their consent and, in some cases, it is against the law to use them at all because they are seen to involve an unacceptable level of assault to human dignity. However, the same behaviours in persons with a developmental handicap may be treated by aversives.

One has to wonder why there is such a difference in the application of aversives to varying groups of people. The difference may be due to the extreme vulnerability of persons with a developmental handicap and the failure of our North American society (including psychologists) to provide them with protections equal to other persons. This existing differential application of aversives should be a matter of concern.

Responsible Caring

The second ethical principle espoused by Canadian psychologists is Responsible Caring. This principle requires psychologists to be concerned about and try to contribute to the welfare of their clients and, at least, to do no harm. To meet this expectation, psychologists are asked to ensure that they properly assess their client and his or her situation so that they can discern what might benefit or harm that client; that they do everything possible to minimize harm and maximize benefits; that they correct harm when it occurs; that they be particularly careful to protect the welfare of vulnerable clients; that they maintain their competence; that they understand their own backgrounds and beliefs and how these might influence their judgments; that they make every effort to ensure that psychological knowledge is not misused to harm others; and that they have the humility to recognize that disciplines, theories and viewpoints other than their own can also be of benefit. Psychologists are concerned about psychological harm (fear, humiliation, mistrust, reduced self-esteem), as well as physical harm.

The vast majority of psychologists involved in the use of aversives are firmly convinced that their use will be of benefit to the individuals concerned. There is substantial research suggesting that such methods can reduce severe behaviours. But is this enough? A closer look at the principle of Responsible Caring would suggest that scientific evidence of effectiveness is not sufficient to assume that the principle is being honoured.

A major problem is the limited framework that is often used to assess the needs and situation of the person with a developmental handicap. For example, the Ontario Ministry of Community and Social Services document, "Standards for the Use of Behavioural Training and Treatment Procedures in Settings for the Developmentally Handicapped" (1986), is thorough and clearly written. However, it is limited by its "behavioural" focus. Assessment of the circumstances surrounding the behaviour of concern and methods already tried to reduce the behaviour is restricted to a behavioural model. Although a medical examination is required (the parameters of which are not specified), there is no reference to assessment of other contributing factors, developmental, communicative, emotional or systemic. When the problem is defined as solely behavioural, then the treatment invariably is also behavioural and may include the possible use of aversives. Considering the seriousness of the problem behaviour, the situation would seem to cry out for a multi-focal, multi-disciplinary approach to assessment and finding solutions. However, guidelines for the use of aversive procedures rarely address this issue. Once again, I know of no other population for which such a limited assessment model would be considered acceptable.

A second major concern within the Responsible Caring context is the misuse of behavioural methods (including punishment) by those who have not been adequately trained and are not adequately supervised. Such a problem is not unique to behavioural methods. For example, one can also find the misuse of paradoxical intention by novice family therapists, of physical control by the novice child-care worker and of structured learning by the novice teacher. The pressures of being new to a job or of being in a high-stress situation without adequate training and support can lead to an unfortunate "ripple effect" in which methods that may be appropriate in a limited set of circumstances and in which the novice worker has obtained a limited amount of training are applied inappropriately and with harm to a broad range of circumstances. Some years ago, Webster (1977) reported an incident in which a teacher of children with autism came to him with a request for help in implementing a behaviour modification program (using electric shock) for a child who was repeatedly banging his head. Through a series of questions, Dr. Webster discovered that the child would not bang his head when sucking on a popsicle and he suggested that a dentist look in the child's mouth before the implementation of any aversive behavioural program. Sure enough, the child had a serious dental problem! We like to think that we are more sophisticated now and that such a mistake would not be made. At the very least, we would not now consider the application of electric shock for such a circumstance. However, the important lesson from Dr. Webster's tale is that we can inadvertently create a restrictive atmosphere (in Dr. Webster's example, a punishment-oriented one) for workers by concentrating too heavily on a single model. We need to take a close look at what we offer students in community colleges and universities. Offering a variety of courses reflecting the same single-model orientation is unfair to students and can lead to misuse and harm.

Integrity in Relationships

The third ethical principle, Integrity in Relationships, requires psychologists to be fair, impartial, straight-forward, and open. This includes avoidance of misrepresentation and conflict of interest, and an awareness of one's own biases and how those biases might affect one's attempts to be accurate and open.

It was openness to behavioural techniques in the early 1960s that brought a breath of fresh air to services for persons with a developmental handicap. Until that time, large numbers of persons lived in facilities that provided food and clothing, but virtually no educational programs, life skills training or work experience. This had happened because of the mistaken belief that those with a developmental handicap could not learn and, therefore, should not be taught. Psychology had contributed somewhat to this "conventional wisdom" when Binet developed his intelligence test to distinguish between those children who could be taught, but were disadvantaged, and those who "could not be taught." Over the past twenty years, psychologists have made enormous contributions through the application of learning theory and behaviour modification concepts to the development of educational, life skills and employment programs. This has been done to the benefit of all concerned. However, my experience over the past year or two with psychologists working to find alternatives to the most intrusive aversive methods has led me to believe that there is now a lack of humility and an over-reliance on concepts of learning theory and behaviour modification in the application of psychology to the difficulties of persons with a developmental handicap. To take the next step forward, we need a renewed openness to new methods, ideas, levels of analysis and theories. Instead, I have been struck by the sometimes adversarial stance taken by psychologists against the application of new or different models and by the missed opportunities for collaboration and improvement in our understanding of human behaviour.

The use of euphemisms in the literature on aversive methods is another problem related to Integrity in Relationships. This seemed to be a trivial matter until the seriousness of the misrepresentation or "whitewashing" became apparent. When a pinch is described as "finger and thumb pressure applied to the back of the neck" or teeth being brushed with Listerine is described as "oral hygiene punishment" or a hood being placed over the head and upper body is described as "visual screening," my reaction is to ask: "What are they trying to hide?" At the very least, such euphemisms lack straightforwardness; at worst, their use is motivated by dishonesty and a desire to mislead the reader.

Another problem is that some psychologists, when refuting concerns about aversives, imply that the concerns come mainly from the uninformed lay public who react "emotionally" to the use of aversives without an understanding of their intent or benefit. This is less than accurate. There is a substantial literature, written by psychologists and other informed professionals, expressing serious ethical concerns about the use of aversives, especially those that are considered to be "highly intrusive."

Responsibility to Society

The fourth ethical principle espoused by Canadian psychology, Responsibility to Society, holds that there is no such thing as a "value-free" science that can pursue its own course with little regard for the needs and context of society. Psychology and psychologists exist within a society that will influence and be influenced by psychology and, therefore, the discipline needs to ask its questions and use its resources with attention to that society. As with any other profession, psychology has a responsibility to avoid being misused for political purposes and to act to the benefit of society as a whole. In carrying out their activities, psychologists need to respect existing beliefs, structures and norms that support such principles as Respect for the Dignity of Persons, Responsible Caring, and Integrity in Relationships. When these principles are not supported, psychologists have a collective responsibility to speak out and to attempt to correct existing problems.

On the positive side, I believe that psychologists generally have been responsive to societal concerns about ethical issues in the use of aversives through the development of strict guidelines for their use and through dialogue about the ethical issues. Notwithstanding the many problems outlined in this paper, most psychologists working in the field do what they can to ensure that their facilities respect and safeguard the rights of their clients, work toward their well-being and engage in relationships with integrity. However, the "critical self-evaluation" attempted in this paper would indicate that we need to do more to honour the principle of Responsibility to Society. As a group, psychologists' concept of "rights" may be too limited, their imaginations too restricted in developing alternatives and their investment in maintaining the status quo too inviting. We cannot ignore the concerns that continue to be expressed in spite of the existence of clear guidelines for the use of aversives.

One technique that has been used by societies, wisely or not, for shaking a discipline out of a perceived "rut" is to declare certain methods no longer permissible. This has been tried, in some jurisdictions, with such methods as electro-convulsive therapy, certain drug therapies and use of "the quiet room." In the latter example, in particular, I have seen some remarkable changes in a staff's ability to find other, more positive methods for changing behaviour and helping a child to better internal control and self-understanding when a particular restrictive technique is no longer available.

In my opinion, our present "rut" is reflected in the level of financial and human resources that continue to be used to develop and research aversive methods, without a similar level (at least) directed to the slowly burgeoning and promising alternative methods. I look with optimism at the increasing number of psychologists who are directing their energies to the exploration of such alternatives.

3.

Redefining the Problem: An Alternative View of Difficult Behaviour

Douglas Logan

I feel the need, given the points that follow, to begin this by stating clearly that I agree it is necessary for us to act to protect people who are in danger of being harmed by acts of aggression and other forms of problematic behaviour. I also agree that it is necessary to protect people who act their aggressions out on themselves. Even so, I intend to argue from the perspective of an administrator that we can provide these protections without being intrusive or delivering harm while we come to understand and respond to alternative ways of answering the problems with which unusual behaviours confront us. These alternatives will be found by focusing on two basic principles: the first is that our efforts should be directed towards changing our service structures to suit individuals, rather than individuals to suit structures; the second is that we must re-examine our definition of equality with the goal of teaching ourselves and the general public to be more tolerant of "differentness."

I know a mother whose teenaged daughter, I'll call her Shelly, has been diagnosed as having Prader-Willi Syndrome. People who have this syndrome must cope with a constant desire to eat, along with an inability to assess whether their bodies have had enough nourishment. You will appreciate that the parents of a teenager with Prader-Willi have their work cut out for them. Shelly's mother, however, must also cope with a daughter who occasionally engages in self-injurious behaviour. Yet, even though she has these very difficult issues to deal with, Shelly's mother does not describe her daughter as a problem, but as a challenge: a challenge to understand, a challenge to help and, often, a challenge to love. I believe that what is significant about the mother's way of describing her daughter is that the mother has put the responsibility of understanding and coping with her daughter not on Shelly's shoulders, but on her own. She is prepared to accept Shelly's uniqueness as an individual without allowing her individuality to be obscured and overshadowed by the difficult problems she presents to others.

What Shelly's mother is helping me understand is that we who are in the "service system" must learn to see the people we struggle to support in the same way — as unique individuals who challenge us to respond to them as autonomous beings who may have some things to teach us, and not as a composite of problems to be solved.

If we accept an attitude of being challenged to learn, we will be forced, instead of simply looking for ways to eliminate behaviours, to be more prepared to accept people as they are while we try to understand what drives them to act in so many different ways. The answers that we discover will sometimes be embarrassingly obvious.

Curtis is a very inquisitive twelve-year-old-boy who lives with his single mother. He has been diagnosed as having Tuberous Sclerosis, a syndrome that results in the growth of tumours on various parts of the body, including the brain. The result can be, as it is in Curtis's case, serious impairment of intellectual functioning and of the ability to learn.

Curtis and his mother live in a small house located on a fairly busy road with a yard that goes right to a river. Curtis's mother was seriously concerned about her ability to supervise him so that he wouldn't wander, out of curiosity, either into traffic or into the river and come to serious harm. She consulted with a behaviour therapist who recommended a variety of technniques she could use to change Curtis's wandering behaviour. She didn't feel any of these would help her, even though the therapist was confident that his "technology" would work.

Since she wasn't prepared to follow his advice, he withdrew his services. What Curtis's mother knew and the therapist didn't was that Curtis's wandering behaviour was a *symptom* of the problem, not the problem itself.

Attempts to change his behaviour would have required intense effort and a great deal of time with no guarantee of success, so she applied for financial assistance and had a fence built around the yard. She no longer has to worry about his wandering.

I was the behaviour therapist at the time, and this is but one of many humbling lessons I have been taught by parents about taking the time to understand their challenges. I was so arrogant about the skills and technology I had to offer that I was unable to see beyond the superficial issues presented by Curtis's behaviour. I would have done Curtis and his mother no good had I insisted on attempting to change his behaviour, because his behaviour was not the "real" problem; his safety was.

Other answers can be more difficult for us to discover.

Bill is in his early thirties and lives in a group home after having spent most of his life in an institution. Bill is in excellent physical condition and likes to run — not walk — everywhere he goes. He is comforted by regular routines and will express displeasure if they are disrupted. He also keeps very much to himself and does not talk to others about how he is feeling.

Recently, he began having difficulty finishing his meals, wouldn't stay at work, began breaking his possessions and threatened to hit some of the people he is living with. During a serious discussion by group home staff about programs and punishments that could be implemented to eliminate Bill's aggressive behaviour, someone mentioned — in passing — his refusal to eat his favourite food. By sheer chance, it turned out that a regular dentist appointment was scheduled for the next day and the decision was made to implement no behavioural program. Bill's entire mouth was discovered to have been full of painful cankers. The dentist prescribed antibiotics and Bill's aggression and agitation disappeared.

Once again, the behaviour was only a symptom of the real problem. Staff needed to learn that Bill has unique ways of dealing with illness and pain. In his case, problem behaviour is the language used to say "help me," and behavioural interventions would have run the risk of compounding his pain.

The stories of Curtis and Bill illustrate the positive outcome of looking beyond the behaviour to understand the real problem. The next story is different because we have still found no answer.

Steve is a thirty-six-year-old man who has been diagnosed as having schizophrenia. He has no close friends or family and has spent all of his life since early childhood living in environments where the only significant people he knows are paid professionals. While he is an extremely well-liked and engaging individual, Steve has been known to set fires and will become extremely agitated and aggressive when confronted by changes to his routines or by behaviour in others that he considers inappropriate. He has been on, and continues to be on, an astonishing variety of behavioural programs and medications that are intended to change or eliminate the problem behaviours he presents. There have also been frequent occasions over the past few years when his ability to relate to others has become so problematic that he has spent much time in psychiatric facilities. At no point in the past five years, if not longer, can we document that institutional or other professional involvements have resulted in positive change for Steve.

Indeed, the systematic focus on treating the symptoms of Steve's behaviours, attempting to control them through punishment and drugs, has not answered the challenge he presents to us. If the technology has not worked, perhaps the answer does not lie in trying new approaches or treatments, but in learning to accept the unique challenge Steve presents — that which is different about him — and not "doing" anything.

The issue, I believe, is not the problem of behaviour as described by the above three individuals, but the problem of our response to the challenges presented by their behaviour. Perhaps we have learned too much to see our successes measured by changing behaviours and not nearly enough in finding ways to accept and understand people like Steve who are different from the norm. Certainly Steve, Bill, Curtis, Shelly and hundreds of others like them are entitled to the skills and security we have to offer them. However, I no longer believe that the challenges they present will be answered through the development of new technologies — aversive, intrusive or otherwise. We must learn to accept that there is not going to be a successful new "wonder drug" or other alternative. Instead, let us rethink the way we respond as service providers and professionals so that we can learn to see the real problem rather than the symptoms. The following questions are intended to stimulate this thinking.

(i) *Are we who are in the service system the solution or the problem? Does the rigidity of our administrative structures help or hinder?*

I administer a service organization that provides supports for people with developmental handicaps. The services offered include group homes. There are two individuals who live in one house — through no choice of their own — who dislike each other so much that we have to deal with their fighting, arguing and threatening each other with violence.

Many people worked intensively and creatively one summer and early fall with another very challenging individual, hoping to encourage her to be an active participant in community life. Their work was focused exclusively on her and shaped according to her uniqueness as an individual. Although it appeared that this focus was being quite successful, we foolishly insisted on having her attend school, a system that is not individually focused and not usually prepared to respond with much flexibility to individual needs. The result was conflict and a dramatic increase in problem behaviour.

But why should we even be surprised by problems? The real issue surrounding their behaviours is that we have forced these people into situations where they feel they have no choice but to respond as they have. It is we, not they, who are the problem, and it is we, not they, who should be under pressure to change.

(ii) *Do we have a genuine commitment to use all of our resources to understand and respond to the real challenges of problem behaviours?*

I wonder how often aversives and other punishments are used because they are ultimately easier to implement and are "cost effective." I posed this issue to a behavioural psychologist who said he was inclined to agree with me, not so much because people using aversives were lazy or cruel, but because they, and the systems in which they worked, were unprepared to cope with the problems not punishing someone with a challenging behaviour would cause. For example, if the service structure itself is the real cause of the problem behaviour, as is the case of the individuals mentioned above, and punishment is used to control only the symptom of the problem (fighting, aggression, etc.), then the only alternative that would seem appropriate if punishment were not to be used would be to change the system itself. This would mean giving the people who dislike each other so much the right to live where they choose so that they would not be forced to put up with each other. It would also mean a complete refocus of the school system from groups of like problems towards individual uniqueness. What is unsettling about these possibilities for administrators like me is that our experience, training and practice is based on the development of systems that can be monitored and measured. The concept of individual uniqueness, however wonderful it sounds, is by definition unsystematic and apparently, therefore, beyond measurement and control. It is sometimes quite frightening to think about not being in control, but an acceptance of this is essential if we are to be true to our commitment to use our resources to help.

(iii) *What other group of people in our society is subjected to as much punishment and behavioural technology as people with developmental handicaps?*

In spite of all the time spent on research and data collection, I believe strongly that the question of whether or not these aversive techniques are effective is irrelevant. What is relevant is that we are prepared to use these tools at all, and what that says about how we view these people. Many before me have made comparisons between the use of aversive technologies and torture. Others have talked about how the treatment of people with handicaps so closely resembles that of the underclasses of totalitarian and racist societies like South Africa. As outrageous as these comparisons may seem, and as defensive as they may make us feel, I think we should use them to ask ourselves how fully human we see the people we treat with aversives as being. This is a very unsettling question to expect people in the behavioural and social service communities to ask of themselves, because it implies that they have been acting almost as criminals. This, of course, is not the case. Almost all professionals are concerned and caring people with a genuine commitment to helping others, who would be appalled to think that they were truly causing harm. Nevertheless, the question remains: would we treat someone we genuinely saw as our equal this way? It suggests the need for a significant re-examination of our attitudes towards people with developmental handicaps.

Why do we have such a difficult time accepting the "differentness" of people with handicaps, particularly those who have behaviours that we feel are unacceptable? Some of the members of our society are different from the norm in dramatic physical, emotional and/or behavioural ways. Rather than taking the time to recognize, appreciate and accept what this differentness has to teach us, have we sought too much to sanitize, equalize and normalize everyone within the bounds of a mythical standard? We look to encourage everyone to act the same and behave within the parameters that we think are acceptable but, by placing this expectation on a group of people who do not have the physical, intellectual or emotional tools to do so, do we not, by definition, guarantee their failure? And when they have then failed, does this make punishment more acceptable?

Julie is a twenty-year-old woman who, from a very young age, has presented a number of quite disturbing aggressive and self-injurious behaviours. Unfortunately, these began to threaten the other children in the family. When her parents went for help, they were told that there was nothing available to them in their community and that she should be sent to an institution for the developmentally handicapped. Although this was an extremely difficult decision for the family, they felt they had no choice and reluctantly agreed. Julie lived in a number of institutions for nine years. During that time, a variety of different techniques were attempted in an effort to change and/or eliminate her problem behaviours. Although these techniques included contingent electric shock, none resulted in effective long-term change.

In the spring of 1986, Julie went home to visit with her family for a day and for a number of reasons they refused to send her back to the institution. The family was severely criticized by most of the professional community and were accused of, among other things, not acting in her best interests and of placing her and others in danger. For the past two years, various community agencies have attempted to work with the family in an effort to give them the support they require and to change Julie's behaviour.

The self-injury and aggression still occur. Julie continues to test those around her to the limits of their creativity and endurance to find the answer to her challenge, so far without significant success, except that she has been and is with her family and is at least in a small way accepted for being who she is. She is not "cured" and cannot be proven to be "better" behaviourally than when in the institutional system, but she is certainly no worse and now has a family along with a small circle of others committed to facing the challenges she presents.

That is the point. Of course, it matters that she may hurt herself or others and of course we must act to prevent this, but if we accept her as our equal, she has the same entitlements as we do — to family and friends, to community life and acceptance. It is these things that are most important. It is up to us not so much to change Julie, Steve, Curtis, Bill or Shelly, but ourselves to ensure they have the choices and opportunities that we all take for granted.

Living in the Community: George

Jill Leach

"George, you have a visitor."

Silence.

"George, do you feel well enough to get up for a bit?"

The shape underneath the blanket kicked his legs and rolled over in response. We tiptoed away, smiling at what had just happened. I could have played this scene with my own son.

"I'm really sorry about this. His flu came on fast and furious." Robin smiled apologetically at me as we went to the kitchen for coffee.

The day was bright and the view of the mountains from the kitchen was almost overwhelming in its beauty. We spent the afternoon talking about George, bathed in the warmth of an early spring in Vancouver.

At seventeen, George could be any teenager in this city. Tall and remarkably handsome, he chooses a "trendy appearance." Similar to my own teenaged son, George's hair is slightly spiked and he dresses in baggy pleated pants, hi-tops and baggy shirts or sweaters. To think of him as handicapped seems absurd; none of the labels fit.

Yet just two years ago, he was considered uneducable. At fifteen he was still in diapers, his parents having been told he would never be toilet trained. Luckier than most people who've lived in institutions, he has had the support of a family unafraid to intervene on his behalf.

George spent his childhood in several institutions in Ontario before being transferred to British Columbia. His father had begun working near Vancouver and the family insisted George be close to them. Shortly after his admission to a B.C. institution, it was closed and George moved into the community.

The first year in his new home was rough. When agitated, George was abusive to both himself and others by slapping, biting, or chewing on hands and arms. Even now his hands are scarred from this behaviour. Records at George's home log three hundred self-abusive incidents per day when he first moved there.

George was non-communicative and uncooperative in the beginning, trusting no one who worked at the house. His abusive behaviours were not the mindless acts of an uneducable child, but wild responses to his own neglect and suffering. Staff recall a time when, shortly after moving into the house, it became apparent that George was terrified of the plant sprayer. Documentation shows that a plant sprayer filled with ice-water was commonly used for behaviour management in one of the institutions where George had lived. Whenever George bit himself or anyone else he was sprayed in the face or mouth. The result was not that George stopped biting, but that he developed a horror of plant sprayers and ice water.

Unable to express himself verbally, George's outlet for his anger was expressed in abusive behaviours. Therefore, the aggression displayed in the punitive actions to control those behaviours would only compound the problem.

Further investigation shows that George's inappropriate expression of anger and frustration was not only managed by squirting ice water at him, but also by drugs and physical restraints. His mother recounts a time when, in one of the institutions in Ontario, George did not recognize the family during a visit. Upset by this, his parents discovered he had been severely drugged in an effort to control his abusive behaviour. Furious, George's father took him home to withdraw him from the drugs and immediately transferred him to another institution.

Unfortunately, George did not fare any better there. When the ice water treatment did nothing to curtail George's biting and slapping, physical restraints were used as well as an elaborate ritual of laying him face down and tying his legs and arms out in spead eagle fashion.

By the time he moved into the home where he now resides, George was an emotional mess. Suffering from extreme mood swings as well as years of humiliating and negligent treatment, he was initially unresponsive to the community approach.

However, with the tireless support of an individual staff person, George began to learn to trust his new situation. Within a year, he was completely independent with toileting and remains so. In fact, this adolescent, once considered hopeless, who at fifteen was uneducated and diapered, is now in a one-to-one program in an integrated classroom and becoming adept at asserting his needs and making age-appropriate choices for his life.

What happened to initiate such a striking turn in George's behaviour? His parents had been told to expect nothing of him — ever. At an early age, he had been condemned to a life devoid of challenge and consistent daily human interaction. Participation in society was considered impossible due to his excessive and constant physical abuse.

As luck would have it, George found a person at his new home who was willing to see beyond his labels and to anticipate and act on his potential. With her no-nonsense manner and willingness to walk the extra mile for George, he began to trust that she would not hurt him. A bond developed between the two and, in an effort to seek approval, George began to model his behaviour after hers. Parental participation and support rounded out this approach and supplied the reinforcement necessary for George to trust and accept this changing life-style.

Intensive one-to-one life skills facilitation, patience and an unfailing positive approach afforded George the opportunity to relax and begin to develop the person we now see.

"He's a stereotypical teenager."

Robin speaks highly of the wonderful person George has become. "He's so funny. He loves to joke around. Let's see," she continues, "he loves food, loud rock and roll — the louder the better — and cars. When he gets dressed up he's 'lean and mean' — ready to dance. Oh yes, he likes to sleep in on the weekends. Like every teenager I've ever known, he's impossible on Saturday mornings!"

The person who has evolved from the hostile, abusive young man of two years ago is happy. George is socially oriented, loves babies, school, and has learned to communicate well with signs and gestures.

The pivotal point in this change in George seems to originate with his understanding of self-respect. Once he fully comprehended that the respect he felt from staff was permanent, he began to respond to the principles they taught him of self-direction, ownership and responsibility.

Like anyone else his age, labelled handicapped or not, George was expected to behave appropriately. Consistent modelling on the part of staff and family not only reinforced for him what appropriate behaviour involves but also indicated to him that he has the ability and opportunity to choose for himself.

As Robin spoke of George's continued personal growth during the time she had worked in his house, I kept thinking how normal his life had become. George still has difficulty trusting that his requests will be acted on to his benefit and hesitates to approach others if he needs something. However, during the last eight months he has become more consistent in his self-assertion.

While continuing to recognize, develop and respect himself, George is also learning to turn that respect outward. His abusive approach to others is being replaced with an understanding that, while we all have bad days, there is no justification for taking anger out on those around him.

In less than three years, George has developed the degree of self-control it takes most people an entire childhood to learn. He is proof positive that great things can be achieved by gentleness, patience and praise. Fifteen years of a punitive and negative approach have not been entirely eradicated. However, George's potential is only now becoming visible and his future holds gifts or promise far beyond any previous imagining.

"Some days I fully expect to see George cruising down the street on a skateboard, wearing trendy shades, smiling at his accomplishment. It's hard to believe that less than two years ago he couldn't even go to the bathroom by himself!"

Robin looks at a picture of George on the living room wall, then stares out into the brightness of the afternoon, lost in her own thoughts of what George's future might hold.

4.

My Sister Kelly

Mary E. Collins

The difference between two people's lives can be as extreme as life and death. This is a true yet horrendous story of a life seen through the eyes of another. It is about sisterly love, devotion, trust and dedication, and is written to honour my sister Kelly and her nuclear family. Hopefully, it will serve to ensure a better quality of life not only for my sister but for all people who require very special needs.

This story is about Kelly who, for the last two decades, has lived a struggling existence within the walls of an institution. As a young girl, Kelly was diagnosed and labelled "mentally retarded" with severe behavioural difficulties. She currently lives in the Southwestern Regional Centre in Cedar Springs, Ontario. She is placed in the behavioural modification unit where various forms of controversial and inhumane treatments have been used with little or no success. She has been receiving these controversial treatments for the past twelve years.

The following are my recollections and feelings throughout the twenty-eight years of Kelly's life. My first memory of Kelly affecting my life was when she was about seven years old. My parents had taken me with them to the place where Kelly had been sent to make her well again. I was told by my parents that Kelly was very ill and had to go to a hospital (Palmerston) where she would receive the care needed to enable her to come home again. Driving up to the hospital, I was amazed at how big and imposing it was.

My parents asked me to wait out in the car and they would bring Kelly out to see me. I was disappointed about not being able to see where Kelly had been living, her room, the people she lived with. My disappointment grew further when my parents returned to the car without Kelly. I demanded to know why she wasn't coming home. I knew then that something was very wrong. I was full of questions and sadness. My parents gave me no answers, nor any hope of knowing what to expect.

As I grew older, I soon realized that Kelly would not be coming home for quite some time. She was allowed to visit with her family for traditional holidays only. She would always then return to the hospital. I can recall always volunteering to go for the ride to pick her up, always being so excited that Kelly was coming home for a while. At times, the visits were very intense.

After the novelty wore off, Kelly's aversive behaviour would surface, self-abuse and tantrumming. She was getting steadily worse, as was our family's frustration. We were finding it difficult to cope. My distressed mother wanted more to be done for her. She looked to medication to help Kelly's constant lashing out.

At this point, Kelly became malnourished due to lack of adequate care. She plunged into deep depression because of drugs that made even her own mother unrecognizable to her. Furious at the state Kelly was in, my mother had my sister rushed to the Children's Psychiatric Research Institute in London until she had regained her health. My mother then decided to bring Kelly back home until some alternative treatment could be found.

It was at this point that Kelly, perhaps sensing her family's despair, became extremely aggressive towards those around her. The bouts of head banging, self-biting and throwing objects became common. My mother felt torn and helpless when she realized she was not able to reach her tormented daughter. She was determined to look for an appropriate place, better suited to cope with Kelly's fits.

It was like living with a time bomb. Kelly had to be monitored constantly. One minute she would be happy and smiling, the next, banging her head violently against a wall. My mother had no choice: the only alternative left was institutional life.

Application was made to admit Kelly into the Southwestern Regional Centre (S.W.R.C.). She was immediately placed on a ward with several other children. The ward was full of strangers, loud noises and confusion, a highly inappropriate setting for her to be in. This affected her behaviour, which the staff tried to control with various drugs. Soon her body built up an immunity to them so that they had little or no effect.

My visits to see Kelly at S.W.R.C. had become a regular part of my life. I became very used to seeing Kelly with others like herself in an institutional environment, living in a world foreign to me.

I cared for Kelly very much and wanted badly to be a part of her life. I sensed her loneliness, with her cries of pleading to come home again. I tried desperately to help her with her pain and wanted only to see her happy. I enjoyed doing things with and for Kelly. On home visits, all my time was spent with her. Being an extremely active child, I often took Kelly with me on many long walks, bike rides and trips to the parks.

Kelly loved to go with me everywhere. We grew very close. We were very special to each other. She knew how much I loved her. It felt good for me to make her feel happy. If I was not with my mother for a visit, Kelly would ask her several times why I was not there. She learned to expect me for every visit. It was not difficult for me to live up to that expectation.

At times, because of my mother's and my having little faith in the institutional system, we would arrive unannounced. We would sometimes find Kelly heavily drugged and in restraints, often having badly beaten herself. It was tormenting to see her in these conditions. We felt helpless.

Kelly, on her good days, was very much a pleasure to be around. She would be so happy, laughing and enjoying the small things in life. During these happy days, it was difficult to see that an angry unhappy child existed in her.

After a few years of living in S.W.R.C. and coming home for regular visits, Kelly's bad days were becoming more intense. She posed a high risk both to herself and her family, for whom it was increasingly difficult to deal with the sorts of problems she created. She was a very demanding child and her needs were much greater than our family was able to meet. We tried to make her understand that she must have some sort of self-control; that her self-inflicted pain was also causing pain for the people who loved her dearly. She would always be apologetic for the pain she would cause.

Unfortunately, soon the visits were too intense for everyone involved to deal with. They would result in ambulance rides or staff intervention, each time leaving her family in an emotional turmoil. As the years passed, Kelly's aversive behaviour began to take its toll. Her physical appearance was rapidly deteriorating. She had pushed out her front teeth with her tongue, and her body scars, as well as her mental scars, were deepening. She was well on her way to self-destruction.

My mother knew something had to change in Kelly's life. She met with several professionals at S.W.R.C. It was agreed that Kelly needed to be put in some kind of behavioural program. She was to be transferred to the Behaviour Modification (B-Mod) unit on a temporary basis. We attended an introductory meeting that outlined the types of aversive therapy/techniques currently being used.

These techniques involved time out, contingent exercises, shock therapy (cattle prod), manual restraint, bed restraints that sometimes inflict pain, lemon squirts in the face. I was immediately opposed to these "treatments," especially the shock therapy. I did not feel or see how these treatments that sometimes inflicted pain could help Kelly lead a pain-free existence. I pleaded with my mother not to consent but, after several hours of discussion with me, I came to the unsettled conclusion that there were no alternatives. After all, these people were professionals who would do their absolute best to help and care for Kelly.

In 1975, when Kelly was around sixteen years old, she was transferred to the B-Mod unit where she would stay until her "unsocial" behaviour showed some type of decrease. She was placed with others who exhibited similar problems. Treatment was in full swing, along with new experimental drugs. However, the onsets were becoming more regular and with deeper intensity. Kelly was still unable to exhibit self control.

Kelly was extremely strong, physically and mentally. She was not ready to let these people control her, and rebellion was her ally. She was becoming increasingly angry and confused. She just wanted to go home. This place did not make her feel safe. Above all, she was losing all control. She was becoming completely disoriented, which I felt was due to the various types of drugs used. The main treatment being used at this time was restraining. Kelly always had her hands tied, usually behind her back. She was soon used to being tied and would often ask for this treatment to be done. She was confined to bed in four-point restraints. Her sleeping patterns were irregular. So again, drugs were used to help her sleep.

She was spending weeks, sometimes months in bed restraints. With her incredible strength, she was able to wrench herself out of these restraints. Physically she was suffering. She developed many bed sores. Her head was balding in areas from continuous rubbing. Her eyes as well as her body (possibly drug induced) began to tremor constantly. Cataracts developed in both eyes, and her vision diminished. She consistently abused her eyes, which only increased her anger and confusion.

My mother was unhappy with the care Kelly was receiving at B-Mod. She was suffering again from malnutrition. Her unhealthy environment was not helping her. My mother decided to bring Kelly home again, we slowly began to nurse her back to health. One of us was with her at all times. Kelly at this time, was uncontrollable and we were forced to use bed restraints. Other than this, we did not try to control her behaviour. We were just glad to have her home where we could tend to her personal needs and make her feel safe. We did manage to build her health back up to a point, but it was very difficult for us; the strain was beginning to show.

We could not reach Kelly again. She had to be sent back to S.W.R.C. We had not lost all hope but we were at our wits' end. Where were the answers? It had been almost a year and she was still in restraints. Again she was beginning to weaken and deteriorate. I felt Kelly's pain. I could see what she was going through. I felt so scared for her. She needed me so badly now and I felt so helpless.

She was losing her fight. She was too tired to struggle anymore. Kelly fell very ill due to an infection she developed on her tail bone from constant restraints. It was quite serious. She was admitted to the infirmary at S.W.R.C. Her condition worsened and my mother had her rushed to the children's hospital in London. My mother and I were constantly at her bedside. We were never so scared and worried about Kelly's welfare. Once again we seemed to have hit another dead end.

Kelly thoroughly enjoyed her time at the children's hospital. The old Kelly began to surface in the loving and caring environment brought about by the medical staff. After spending several months there, she began to progress for the first time in years. Kelly was a lot healthier and was now able to get out of the bed restraints. She was soon ready to return to B-Mod.

What did the future hold for Kelly? Enough errors had been made. It was time to choose a more effective route. At the most severe point in Kelly's behavioural history, it was recommended that she have neurosurgery or electrode implantation. My mother vehemently opposed these extreme measures. It was very possible that this would leave Kelly as a vegetable for the rest of her life. My mother was not going to risk losing the joyful personality Kelly did show during her happier days. Instead of this serious operation, my mother decided that she would put a stop to all administered drugs and consented only to the behavioural treatments. There were no other answers.

The shock therapy started immediately, but this time it appeared to be more effective. Kelly began to maintain a sort of routine and a willingness to work with the staff. It was during this time that Kelly lost sight in her left eye and retained only partial vision in her right; it became impossible to remove the cataracts because of severe muscle damage. It seemed that Kelly's losing her sight did not have a strong effect on her. She accepted this easily, her aggression and anger had somewhat diminished. In some ways, my mother and I took this as a blessing. We were not pleased, of course, with this newest development, but it seemed to bring Kelly some inner peace.

Since this time (1981), Kelly has not gone through such drastic deterioration as that recorded in 1979-1981. Progress in certain areas began slowly but steadily. Kelly attended workshops on a daily basis, along with swimming classes, she started to produce crafts and received great pleasure in her new accomplishments. At long last, she was a part of her environment rather than a pawn in it.

During that transition period in Kelly's life, she had very limited home visits. It was not advisable to allow more as she had to earn them through good behaviour. So, most family visits occurred at S.W.R.C. When home visits were approved, a staff member had to escort her, the visits were kept very short and she was then escorted back.

Around this time, I had moved to western Canada. I was returning to spend Christmas with my family after a two-year absence. Over the two years, I had corresponded with Kelly via letters and phone calls. I had been informed by my family of her recent developments. Kelly was still doing extremely well. Everything pointed to positive progress with little chance that she would return to her earlier destructive state. This Christmas was going to be very special for our family as Kelly was also granted a home visit, one long overdue.

Shortly before my arrival home, I found myself slightly apprehensive about seeing Kelly again. Seconds after my entrance, I felt instant dread. It was obvious from the faces of my family that they had had a long and tiring night. I ran upstairs and found Kelly in a very disturbed state. She had split her head open wide and the rest of her was severely beaten up. As soon as she realized I was there, it caused her to have another fit. I yelled for someone to call S.W.R.C. Staff arrived within the hour and again Kelly was leaving home. I felt so hurt and disappointed to have come such a long way with such high expectations. Again, her life seemed full of despair.

It was then decided by the family that Kelly was no longer going to come home unsupervised. She needed her controlled environment. Being home only caused frustration. She knew that once the holiday season was over she would be returning to B-Mod. I think this made Kelly even more angry at herself and her life at the institution. It was so difficult for Kelly to express her feelings. We could only guess at what was always so wrong for her.

I returned to western Canada hoping to get on with my life but it was difficult for me to maintain a happy life away from Kelly. Responsibility weighed heavily on me, and an inner guilt for not trying to do more for her. I had always been dissatisfied with her environment and wary of the staff and the various treatments she was still receiving (especially shock therapy).

It was becoming obvious to me that after several years of these aversive treatments, she had become stagnant. She had gone as far as she could in these surroundings. With Kelly being exceptionally bright despite her handicap, I felt she had been deprived of her full potential; I had wanted so much more for her.

Convinced I was unable to do anything, I remained in western Canada for the next couple of years. Slowly, I realized I could not have a future for myself until I at least tried to change Kelly's painful existence. I was much more mature and ready to put some satisfaction into Kelly's life before carrying on with mine.

In May of 1986, I returned home with strong hopes for Kelly's future. After a few months of settling in, I concentrated on what changes I could make. I made an appointment to see the director of the B-Mod Unit. I discussed with him that I wished for Kelly to progress in areas that were crucial to her future. His feelings at the time were that Kelly was doing extremely well when compared with her worst period (1979-1982). No longer on medication, constantly in bed restraints and merely existing, her life was much better now. She was contributing to her environment and this was good enough.

I was not satisfied with his perspective. It had been over five years since her bad period. She had developed in such small areas compared with what I knew she was capable of. It was apparent to me if I wanted any kind of changes for Kelly I would have to seek out other sources. Unfortunately, the institution failed to show me any hope for Kelly's future. I would often ask myself if I was looking for an answer I'd never find? My family tried to help me accept the realities of Kelly's future. My mother understood how important it was for me to sort out my feelings for Kelly. She felt, however, that I had my own future to consider.

But I was very aware of my strong feelings to settle Kelly somewhere. I had to come to terms with her strong effect on my life. I explained to my mother that Kelly's future was very much a part of my future. I couldn't let go of my strong beliefs that something better was necessary to prevent Kelly from destroying herself within the walls of the institution. I could not accept her destiny to be self-destruction. It was not hopeless.

I knew the person Kelly really was. I had reached her and she let me know the real person she was capable of being. She adored me for making her happy, I made what I could of her life fun. Her behaviour did not stop me from seeing the real person. I always felt very privileged to know I touched Kelly's life as no one else was able to do. All my life, she has asked me to take her home. She was never satisfied with my replies and somehow believed I could find the answers she could not find herself. I believed this too. Somehow, I was going to change her life and we both knew it.

My mother often shared with me her experiences and those repetitive feelings of pain and anguish. For so long she had tried to change Kelly's life, but she was unable to perform miracles. She despised the terrible burden that life had placed upon her shoulders. How was one woman to cope with watching someone she loved so deeply try to destroy herself. Although she felt helpless, she never gave up hope for Kelly. Instead, she started to give up on herself. She became very nervous. Her sleeping and eating patterns were irregular. The ongoing stress was turning her into an irrational mess. My mother never had any support from anyone through all these times. She had no one to share the burden with. Early on, my father had developed an alcohol problem, and under stress he would often turn to the bottle. He refused to deal with her problems. Instead, he referred to my mother as incompetent. He offered little or no support. His drinking got steadily worse until eventually he left us and the province. My mother was left alone with the responsibility of five daughters (one of whom is Kelly). My mother crumbled under such harsh burdens. She had to leave her children and receive psychiatric treatment. Her depression deepened and caused a nervous breakdown.

She was hospitalized for the next eight months. We were refused visiting rights since she did not want her children to see her as she was. My sisters and I were left to deal with life on our own. It was so unexpected for us and we didn't understand her illness. We needed her. We were so scared she wasn't coming back to us. My mother eventually got better and was able to come home. She was no longer the same person, but slowly she began to pull our family back together and we learned to grow with her and adjusted to her changes. I could feel my mother's despair and saw her unhappiness. I wanted to see her happy again. So I began to help carry her burdens and taught her to lean on me. I was always there for her, and helped whenever possible. She grew to admire my strengths and these gave her the needed strength to carry on.

The older I became, the more I understood my mother's stress.

I placed few demands on her. Instead, she was able to place demands on me. I somehow was able to put my needs as a child aside. My family's needs were much greater. I desperately wanted to keep my family together. Many sacrifices were made. I'd often miss school to deal with the crisis at home.

When I reached the point in my life at which I realized that my personal growth was bound to Kelly's happiness, I was determined to find alternatives. My mother did not want me to go through the disappointments she had suffered, but she accepted my plans at least to try to find the answers that were so long overdue. Our family had suffered enough and she would support anything that made Kelly's life easier to endure. She, of course, wanted only what was best for her daughters.

With all I had learned, I realized the professionals had not done all that could be done for Kelly. I was able to see the mistakes that had been made and were still being made and that resulted in Kelly's being where she was. I had never been more certain of my feelings about the treatments used.

I understood Kelly's anger and pain and did not blame her for her aggressive behaviour. Everyone in her life concentrated on her behaviour, always dealing with the behaviour. They never saw her as a person. She was always forced to take medication, forced to receive treatments, forced to live where was was not loved, nor properly cared for, forced to eat and sleep. Force ruled her life and it was all around her. Had anyone asked her what she wanted or how she felt? I don't believe anyone ever stopped to look at Kelly for the person she was, or what her capabilities might be. Her needs were ignored. She was treated more like an animal than a person. When she would become upset, people would rush at her, hold her, tie her down. Then came the cattle prod or squirting liquid in her face. This approach was temporarily effective in stopping her, but it did intensify the subsequent abuse. To Kelly, the world was a big abusive place. Her security became pain. All other feelings didn't exist, so what reasons did she have to change? How could she ever have much hope for anything but more pain? Where was her joy or self respect? Where did she get her dignity and comfort? She had only been neglected and rejected. All her life, she had been told she was a bad girl and made to feel it was wrong to inflict pain on herself.

My feeling was that she inflicted pain on herself because it was the only control she had over her life. Everything else was controlled for her. Her behaviour allowed her to receive the attention and care she so desperately needed. It wasn't the type of love and understanding that each individual needs for a happy life, but it was still getting her the attention, negative as it was. She was well aware of what was expected of her, so she would speak with abuse, it was the only time she was heard. Often during my visits to Kelly's ward I'd find her sitting alone. I very rarely witnessed any personal attention being given to her. It seemed the staff just watched and waited for inappropriate behaviour before they took notice of any one. Kelly was surrounded by others who like herself had behavioural problems. If another member of her ward was having an onset, causing noise and confusion, this would cause Kelly great concern. She in turn would strike out at herself and receive punishment for her own aggresssive behaviour. I had never witnessed a staff member attempting to redirect Kelly's aggression. Kelly was forced to watch the other person's pain and anger and was not supposed to let it affect her. I never understood why the staff were not capable of realizing how the behaviour originated and taking the necessary steps to help her correct it. Isn't each behaviour different? Shouldn't each behaviour be treated and cared for differently? Kelly hasn't been taught how to rechannel her frustration and anger into positive action and understanding. She's only been taught to know treatments that simply cause her more pain.

It was always difficult for me to see the mixed-up world she was forced to live in since I could understand her needs. I resented the way she was treated and after each visit it became more and more difficult for me to walk away and have to leave her behind. I always left with feelings of emptiness. Kelly didn't make it any easier. She always stalled my departure. I'd have to reassure her several times that yes, I would be back. She'd repeat during each visit: "I no come back! I want to come home. I no go back. I be a good girl!" I have heard these words from Kelly a million times. I didn't know how to tell her I didn't know the answers and there was nothing I could do. She obviously did not believe my doubts. She would not give up on me. She needed me to help her. She pushed and I pulled. I didn't want to walk away any more. I heard Kelly's words.

I listened when no one else did. She didn't have to fight or show negative behaviours to receive attention from me. I always gave her my time and offered that little bit of myself with as much understanding as I had. I realized Kelly was very difficult to work with because of her behaviour. There was a lot to deal with if you tried to deal with all of her problems at once. You had to deal with each part of her separately, one thing at a time. She needed constant one-on-one, lots of individual attention. Only then could any improvements in behaviour be achieved.

I could be wrong about my theories, but I am willing to try my absolute best to make Kelly's world a better place for her to live in. I have come a long way with new hopes and plans that Kelly can have a settled life in a community and take an active part in the decisions that affect her well-being.

My devotion to her life has led me to find alternatives to her institutional life. My dreams are now realities. Doors have been opened for a positive future. I thank God for giving me the strength and determination to fight for what I believed in. Kelly is still currently living at S.W.R.C., but with the support of the Strathroy Association for Community Living and the professionals, Kelly is going to gain the chance and freedom to put her institutional life behind her. In a short time from now, I am going to have the chance to walk out of that institution with my sister by my side, with strong hopes of never going back. Our hardest struggle is over. We can see beyond our dreams of tomorrow.

5.

The Efficacy of Behaviour Modification Techniques for Persons Labelled Mentally Handicapped

Bill Downer

In our culture, the incongruities between what we say and what we do are often too obvious to ignore. Within the system of services currently available to those people labelled mentally handicapped or developmentally disabled, this incongruence is particularly apparent.

The most frequently articulated values sought within our service system include: choice, self-determination, community integration and membership, equality, citizenship, personalization, personal support, real jobs, real homes, real friends, etc. These are just a few of the phrases or terms regularly incorporated in agency goal statements, individual service planning systems, or discussions of professional philosophy. Although such values certainly appear to be both sensitive to and supportive of disabled individuals, the reality seems to be that many professionals have little if any real idea of what they mean. By convention, these values are covertly ignored on the level of the individual, even to the extent that what are claimed to be support activities actually incorporate forms and degrees of personal abuse that would not be tolerated in any other sector of our society.

The dichotomy between values and actions in this arena is often concealed, particularly when professionals justify customs that restrict opportunities for personal empowerment with "professionalized" rhetoric. Professional jargon often serves to screen many ignoble conventions from the public eye, and at the same time helps to marginalize and separate the victims of such conventions from society at large. It has also led to the view that these types of practices are only tolerated by the powers that be because the professional is seen to possess an expertise that is superior to normal perceptions of human value and worth.

It is still not readily apparent to all those who have a vested interest in stabilizing rehabilitation that it is absurd to foster two disparate and wholly inconsistent systems of ideology that currently enshroud people who have a mental handicap. One of these is the ideology of integration or membership in the community that seeks to enhance a person's autonomy. On the other hand, there is behaviour modification, normally considered a reactive measure that increases the degree to which an individual is forced to be compliant to external controls.

That encouraging adaptive rather than maladaptive behaviour is a fundamental obligation of the service worker's role cannot of course be questioned. Even the occasional reluctant use of restrictive measures may also be justifiable in limited circumstances. What can be queried, however, is the widespread, indiscriminate and almost religious prominence of "control technology" within any human service field.

This lack of philosophical coherence is a factor that has allowed such widespread application of control technology. But perhaps the single issue that has restricted the ability of the majority of service providers to align themselves in a meaningful way with the emerging philosophies of self advocate control has been simple over-reliance on behavioural therapy practices. The non-availability of practical alternatives and the supremacy of the professional behaviour therapist as the only "legitimized" authority on the management or control of the behavioural characteristics of disabled people may well have led to a conflict in the minds of many service workers between what is ideal (community participation) and what is "practical" (behavioural control).

In earlier centuries, people with a handicap more easily lived within their own communities without being subject to intrusive and controlling measures, such as "service-continuums," pre-requisite skill acquisition, differential reinforcement of other behaviour (DRO), or "lemon juice treatment." Before the cultural transition from the age of faith to the age of Enlightenment and scientific values, religiously based moral commitment to the person who was disabled was regarded as a sign of true humanity. Consequently, the person with a handicap lived in little more fear of censure than any other citizen.

In contrast, many current observers support a view that fully recognizes the political underpinnings of the large-scale control compliance ethic, which exerts so great an influence in social services today.[1] Because the service economy is run like a business and primarily concerned with a production-consumption equation, its interests are more fruitfully served by expansion rather than attrition.

According to this line of analysis, doctors in behavioural modification are by definition, and by the deference afforded to them, an essential component of the dominant professional hierarchy. As such, they are hardly likely to countenance the introduction of competing models of therapy even if they were to be accepted by the rehabilitation fraternity and used on a wide scale. Their interests, as those of other professionals in the service economy, are normally best met by retaining the authority to identify others' "needs." It is this license to define a person as a client, coupled with the moral authority to advise and prescribe to the alleged need, that characterizes the professional. This authority in many instances is supported by the legislators (another dominant professional agency) and often not considered to be useful so much as obligatory. The result is that the individual with a handicap experiences a world of behavioural controls much more extensive than an ordinary life in the community.

At the moment, it is not difficult to argue that, from the point of view of the consumer, rehabilitation has more disabling than enabling characteristics. Yet, it does not need to remain so if we can learn to appreciate the value of each individual as a person.

John was fifty-four years old when we met. He had recently been referred by a local agency to an institutional setting for a wide range of behavioural difficulties. Despite the fact that he was subjected to a rigorous behavioural regime for an extended period, his behavioural profile became increasingly complex. John's difficult behaviours included: non-compliance, avoidance, physical aggression, sexually aberrant behaviour, unsanitary habits, negative attention seeking, verbal aggression, untimely routines and obsessive-compulsion. All of John's behaviours deemed maladaptive were targeted for behavioural therapy and a variety of contingencies were incorporated, including token economy, differential reinforcement of other behaviours, extinction, choice of "reinforcers," earned outings. Varying degrees of success were noted at different points in time. However, a significant increase in all behaviours occurred once the decision was made to confine John to his residence. John's behaviour then became unpredictable even when he was engaging in activities that he was known to enjoy. When he eventually moved to our community his target behaviours were recorded at their highest levels.

Support arrangements in his new community simply included the identification of two persons who made a commitment to develop a personal relationship with John in his new home, and the eradication of all previous behaviour programs. His behaviours were recorded for the following three months.

Within two weeks of his relocation, John's behavioural profile was in no way different from that of other individuals (disabled and non-disabled) with whom he lived and worked. His personality was engaging rather than aggressive and his sense of humour was very much appreciated by his friends. John is now a productive worker whose contribution is valued by his colleagues at work. He is scheduled to earn the same salary as the non-disabled workers at the worksite.

Solutions or alternatives to the restrictive measures often employed with behavioural analysis tend to appear simplistic to the point of being considered unrealistic. As with John, however, transferring choice and a sense of personal power to the individual, along with systematic and trusting guidance in how to utilize it, can often produce powerful and relatively immediate personal benefits to the individual.

Behaviour Therapy and Social Control

Fortunately, the previous few years have fostered the advent of new and more pragmatic service philosophies and methodologies. A number of factors will surely contribute to a fuller grasp of how classical behaviouralism can isolate people from their social potential by establishing artificial prerequisites to social participation. These factors include eco-behavioural analysis, which views the service provider and support worker as integral parts of the dynamic social system in which the consumer finds him or herself. Another factor that is leading to a re-evaluation of classical behaviouralism is the presence of a significant minority of behavioural practitioners who are questioning both behavioural ethics and the long-term benefits to the individual afforded by traditional behavioural therapy approaches.

Although many people now feel that the formation of trusting and respectful relationships provides the only valid basis for an effective long-term habilitative approach, an overwhelming amount of behavioural research has until quite recently appeared to contradict this assumption. While not wishing to question the essential validity of this material, it does appear that much of the behavioural research available to date is questionable when applied within a social context. Reliance upon it may also help to maintain a cognitive distance on the part of direct service providers so that they want to do things *to* people rather than *with* them.

Similarly, classical behaviouralist responses to "atypical" behaviours by the professional almost universally involve the immediate establishment of a relationship in which the person with a mental handicap is held aloof by the caregiver. Often, the person is displaced from our favour simply because they seek recognition. That "attention seeking" can so consistently be considered an unacceptable behaviour is somewhat baffling when we consider how important meaningful relationships are to all human beings and the few opportunities that persons with handicaps have to pursue this goal. There seems to be a pervasive assumption that people with disabilities experience a qualitatively unique experience of the world and of their own oppression.

Our society often assumes that professional "caregivers" are patient, humane and kind people with a great deal of understanding and support to offer. This, of course, is true in some cases. But if it were realized that our single most widely used technology is by definition a dehumanizing one, impressions such as these would not be so commonplace. Community advocates would perhaps emerge to challenge the ethical nature of these efforts. This, no doubt, would be warmly appreciated by many of the disadvantaged people oppressed through the misuse of behaviour modification.

Contingent Electric Shock and Other Aversive Stimulation Procedures

Forms of aversive treatment mentioned in most standards reports include squirts of lemon juice in the mouth, water mist spray in the face, contingent or forced exercise, forced inhalation of aromatic ammonia and electric shock. These procedures are, according to their proponents, designed to be used in situations where high-risk behaviour is exhibited.

In the author's view, such behaviour indicates serious personal and emotional disturbances. How placing these people in special units and shocking them will get to the root of their problem and generate social competence and the ability to develop trusting human relationships is not at all clear.

And in fact a review of published standards on this type of intervention would find few if any clear justifications for "treating" people with such disregard for their personal dignity. While each standard or set of standards is normally accompanied by a section entitled "rationale and support," on the whole, there are few sound rationales for "treatments" that inflict pain or personal discomfort, regardless of whether the individual has impaired intellectual functioning.

If no truly ethical view of humanity can justify such a blatant and systematic disregard for the psyches and disadvantaged position of disabled minorities in our culture, the principle of "normalization" is often used to justify the continued perpetration of these practices. Paradoxically, normalization is most commonly defined as "utilization of means which are as culturally normative as possible, in order to elicit and/or maintain behaviours and appearances which are as culturally normative as possible."[2]

The *effectiveness* of a particular procedure is often cited by behaviour therapists as a primary rationale for its employment, and it cannot be disputed that many behaviour techniques have been demonstrated to be highly effective in weakening targeted behaviours. It may also be submitted, however, that the most significant social benefits of behavioural approaches can be gained from non-aversive techniques when they are employed to strengthen more desirable behaviours while teaching functional skills or tasks. Evidence of how little the latter strategies have been explored is found in the Ontario behavioural standards report, which contains fifty-eight pages of information related to weakening undesirable behaviours as compared to only five devoted to strengthening more acceptable ones.[3]

Humanitarianism — an Ethic

The functional use of aversive intervention is based both on its degree of intrusiveness and on its "effectiveness" in forcing the challenging person to comply with the therapist's demands to "behave." Many studies, however, have suggested that the quality of *rapport* between the therapist and the recipient of the therapy is much more important even than the intervention technique itself. Personal interaction with persons receiving the aversive stimulation was not mentioned a single time in the Ontario government's standards document.

In the non-segregated world, personal relations and the creation of a win-win climate is now considered to be a more effective negotiating strategy than any form of authoritarianism. On all levels of communication, from interpersonal interaction through corporate relations and even international diplomacy, cooperation has been recognized as the single strategy most likely to produce mutually beneficial results. If this win-win model for smoothing interpersonal relations was to be more broadly applied in the field of mental handicaps, it is questionable whether anyone truly in a position to give informed consent would acquiesce to the type of aversive treatment techniques employed by the behaviour modification proponents. In fact, if the opportunity were to be presented in a sensitive and cooperative manner, many people with handicaps could probably assist in the formation of more acceptable alternatives.

Unfortunately the behaviour modification model rarely if ever allows consideration of questions regarding the origin of the targeted behaviour. On the simplest level, questions about why the behaviour occurs may not in most cases be difficult to answer. It can be argued that all behaviour is to one degree or another aggressive in nature, i.e., it is designed to achieve something.[4] If we could spend some time with a person attempting to determine what it is that he or she is attempting to communicate through a particular action, then perhaps we would also be in a position to negotiate a mutually satisfactory solution.

Brutalization

If "weakening" social behaviours through methods such as squirting lemon juice in a person's face is morally questionable, how then does our culture sanction the use of electric shock and other aversive treatments? More importantly perhaps, how can it be that well-educated people who are neither sadistic nor deviant actively participate in such acts, and in what manner do these people manage to justify their actions both to themselves and others?

The simple answer to the first question is that society in this respect has fallen victim to the "white coat" syndrome. In other words, ordinary citizens seldom question the actions of professionals unless these actions have a direct impact on them. Stanley Milgram demonstrated convincingly that people unlikely to be cruel during the course of their everyday existence will administer pain if told to do so by someone in authority.[5] His study involving average Americans has since been replicated in many other countries. He showed that sixty-five percent of persons asked to "inflict" what they were told were dangerous levels of electric shock to "victims" acting as though they were in pain did so. The instructors were wearing white coats but in real life were not professional people at all. Neither did they offer rational explanations for the form of treatment their victims received.

How much more difficult is it for members of our society, even if they are aware of some of the insensitive and inhumane "treatments" perpetrated in our institutions, to question the authenticity of these treatments? If we are told that in Chile or some fifty other countries in the world electric shock is used to stifle political resistance, and that victims of this torture have been shocked in sensitive parts of their body, we would, of course, consider these actions to be barbaric. A part of this conclusion at least is encouraged by the social and political context with which this information is presented to us.

When we hear of electric shocks being applied to people who can supposedly respond to nothing else, and when it is presented in a professional context with a liberal use of jargon that we presume to imply superior knowledge, the effect on us is not so traumatic. No one mentioned the words "victims" or "torture" to describe these procedures, and it appears that those empowered to take care of the disadvantaged members of our society are fully aware of the consequences of their actions. It may not even occur to us, if we review published standards on electric shock treatment, that the majority do not mention body parts that should remain inviolate when the treatment is applied.

The people in our society who "control" disadvantaged people rarely if ever see themselves in an unfavourable light. They have been initiated into their particular creed through an indoctrination process that ensures that successful graduates remain faithful and loyal to the professional standards established for them by their predecessors. A serious breach of these norms could be extremely detrimental to their careers. Gibson, Haritos and Fatouous developed a model to illuminate several ways in which people could be taught to do the unthinkable.[6] This model was developed out of a study and review of initiation processes in a variety of organizations from college fraternities to the Greek Military Police. Presumably, those who have been schooled in the techniques of control are just as vulnerable as anyone else learning how to do the unthinkable.

A Toronto psychiatrist, having examined more than 200 victims of torture, found that many suffer from severe headaches, insomnia and nightmares. They are often withdrawn or they suddenly burst into violent fits of anger for no apparent reason.[7] According to a study quoted by Krajick that reviewed refugees in seven U.S. cities, victims tire easily, are unable to concentrate and think constantly of their torture.[8] While hesitating to conclude that systematic torture is an essential element of our habilitation models, the author, having witnessed the reactions of many persons released from institutional settings, has little doubt that most graduates have internalized their experiences in a similar fashion to those related by torture victims. Having developed relationships with people who displayed many of the above symptoms while indicating fears and anxiety about the possibility of returning to their previous environment, it is difficult to escape the conclusion that most people leaving institutional settings do in fact consider themselves to be victims of a depersonalized and sometimes inhumane system.

Bridgit for example, was a woman who arrived in a family support situation after twenty-nine years of institutional living. At forty-five, she had spent only one of her adult years in a community setting; she lived almost twelve months in a group home prior to arrival in a more family-oriented situation. The community experience was disturbing to her because of the lack of structure and the novel expectations of an environment for which she had been totally unprepared. Although frightened and somewhat disoriented, she often displayed behaviour that was considered to be "unacceptable" to the workers in the group home including crying, shrieking, rocking, and occasional physical outbursts. It was eventually recommended, in view of her behaviours, that she return to the institution.

When an alternative residence was located, the "houseparents" recognized through clues that Bridgit had been insecure in her previous setting. When she became anxious, for example, she would often describe the exact route on which she had been taken to isolation in the institution. Bridgit had also been allowed to bring with her the harness that had been used to restrain her. She habitually went downstairs to her room and brought it up to the houseparents when she perceived herself to be in disfavour, and appeared incapable of understanding that there were other ways to deal with mistakes or misdemeanors than being shackled and made immobile.

Dinkmeyer and McKay's publication, *Systematic Training for Effective Parenting*,[9] recognized that when people are unsure of their position in society and have their sense of "belonging" devalued so that they feel neither useful nor needed, they seek one or other of the following to achieve social recognition:

1. Attention (negative attention being easier to solicit than positive attention).

2. Power (powerful people have greater status, where power involves autonomy in making personal choices. Struggles may result in environments where this is not permitted).
3. Revenge (a stage of discouragement that is really an expression of defeat. Its expression leaves both parties determined to gain control in what may appear to be a power struggle, but may actually be a plea for understanding).
4. Displayed inadequacy (the last stage of discouragement when a person feels totally inadequate to meet the demands of his or her environment and consequently makes little or no effort to do so. When pressured, someone in this position may eventually get angry and if the anger is perceived as the problem and "treated" the cycle only deepens).

Conclusion

Because the rehabilitation fraternity has given credence to behaviour modification as a model of intervention, the quality of the service practices that we perceive to be legitimate and therapeutic has been severely undermined. Without the often unspoken consensus to accept this school of thought as our foremost method of teaching social competence, we may have learned to divest ourselves of the barren congregate care settings that are largely devoid of functional/realistic human experiences and cultural expectations. We may also have learned that the only way to truly respect the dignity of another human being is to treat him/her as *we ourselves would be treated in similar circumstances.*

There are a variety of intervention models based on promoting self-actualization in the social context[10] and determining the optimum person/environment fit.[11] Further investigation of these could be of considerable assistance in counteracting some of the damage that the thoughtless commitment to devaluing methodologies has wrought.

If they refused to support the existing status quo without a continuous evaluation of its human consequences, our governments and funding consignors could ensure that people with disabilities would profit more from the services that we provide for them. In the longer term, paying more attention to the provision of quality of life issues, making available acceptable living environments and providing a more natural approach to treating "challenging behaviours" may prove more cost-effective than current arrangements.

If the provisions noted above were acceptable as an operational ethic, the following recommendations could be framed for serious consideration.

1. That behaviour modification be considered an inappropriate technology for treating the "behaviours" of persons experiencing emotional difficulties particularly when aversive consequences are employed.
2. That behaviour therapists be empowered to assist servicers only with the direct acquisition of living skills such as those required for home maintenance and employment development activities.
3. That "standards" not be considered an acceptable method of monitoring behaviour therapy when they address themselves exclusively to procedural concerns. Standards for service should be developed by consumers and their representatives with advice from professionals of their choice. An inspection procedure should be put in place to ensure that professionals assist in the implementation of rehabilitation rather than assume full control of the habilitative process.
4. That institutional settings be defined as "any environment in which the principle of natural proportion is violated." In practical terms, any setting with more than two persons labelled mentally handicapped would qualify as an institution. This definition would discourage the wide application of aversive techniques while promoting more individualized and carefully considered responses to human needs.
5. That immediate preference be given to the closure of all institutional environments that house twenty persons or more, and that methodologies promoting functional and participated community living be employed for this purpose. In all cases, such methodologies should be incorporated within a paradigm of personal empowerment and self-fulfillment.

Notes

1. See Ivan Illich, *Disabling Professions*, New York, 1979, and Jeffrey Galper, *The Politics of Social Services*, Engelwood Cliffs, New Jersey, 1975.
2. Wolf Wolfensberger, *A Look into the Future for Systems of Human Services with Special Reference to Mental Retardation*, Toronto, NIMR, 1973, p. 7.
3. "Standards for the Use of Behavioural Training and Treatment Procedures in Settings for the Developmentally Handicapped," Ontario Ministry of Community and Social Services, 1987.
4. William Glasser, *Control Theory*, Toronto, 1982.
5. In "Some Conditions of Disobedience ot Authority," *Journal of Human Relations*, vol. 18, 57-76.
6. In "Education of a Torturer," *Psychology Today*, 20 (Nov. 1986), 50-52.
7. F. Allodi and G. Cowgill, "Ethical and Psychiatric Aspects of Torture: A Canadian Study," *Canadian Journal of Psychiatry*, vol. 27, no. 2, 98-102.
8. "Healing the Broken Mind," *Psychology Today*, 20 (Nov. 1986), 67-69,
9. *Parents Handbook*, Chicago, 1976.
10. See, for instance, Herbert Lovett, *Cognitive Counselling and Persons with Special Needs: Adapting Behavioral Approaches to the Social Context*, Toronto, New York, 1985; John McGee et al., *Gentle Teaching: A Non-Aversive Approach to Helping Persons with Mental Retardation*, New York, 1987; and William Glasser, *Positive Action*, Toronto, 1985.
11. Robert Schalock and Rebecca Koehler, *Eco-behavioral Analysis and Augmentative Habilitation Technique — Procedures Manual*, Hastings, Nebraska, 1984.

Speaking as a Parent

Margaret Price

About six years ago our son Jeremy, who was then six, was in a special summer program with a ten-day residential component. He spent seven days on his own with other children in the camp and for three days we joined him there. Many of the children, including Jeremy, were described as autistic.

Although it was very difficult for us, we left Jeremy for the seven days in the program. When we went back to spend the three days with him, we were horrified at what we saw. We saw children naturally reaching out for their parents who were arriving — something fairly exceptional for children with autism. But to the staff, the children weren't "toeing the mark" the staff had set for them; rather they were flapping with excitement. So, the staff physically restrained them. Sometimes their heads were pushed down between their legs. Over the three days, whenever we saw children communicating in their own way, they would be forcibly turned away from the activity and punished. By the third day, we had almost turned the place upside down with our criticism of the methods being used. We were disgusted. We found the whole approach intrusive and confining with no regard for the individual's own way of communicating. In fact, the program was totally contrary to everything that had worked for Jeremy.

At this time, Jeremy was just beginning to speak. We had worked really hard to get him that far using what seemed to be exactly the opposite approach. When he acted up or screamed or cried his guts out in the middle of the night for three weeks running, we figured that he was trying to tell us something. The onus was on us to understand.

At the summer program, we saw Jeremy and the other children subjected to the idea that they must conform and do things the staff's way. We, as parents, felt that the outside world was trying to tell us how to cope with our children but it seems that they were telling us to put the square peg in the round hole. It obviously didn't work. These were so-called professional people who have a "fix-it" attitude that consisted of drug-fixes and sometimes intrusive deterrant fixes. According to them, it is wrong for children like Jeremy to scream and cry to communicate with us. They say the child is not supposed to do that. And even if you have to hurt him to make him stop they believe that's okay.

Parents work so hard to get their children to communicate in the first place. We cried nights, begged him to communicate, said lots of prayers, read everything we could get our hands on — and we said, "Please relate to us. Just look at us. Know we're your parents." And at the point where we just began to make inroads with him he was in this program. He saw us, wanted to come to us and was told he wasn't allowed. He was physically restrained by the staff "for his own good."

By the end of the three days, Jeremy was no longer part of this program or any other program. That was our only exposure to intrusive methods. Now I don't care about the credentials of the person who's recommending these procedures. They are wrong. Our volunteer involvement on local boards of community living associations and admissions committees, reviewing profiles on the management of people's behaviour, heightened our awareness. Through experiences like ours, we begin to get a sense that something is seriously wrong. We're in the 1980s. We certainly shouldn't be where we are today on this issue!

But not all parents have had the experience that we've had. We know of one mother whom we spoke with after a session on alternatives to intrusive procedures who feels completely helpless. Her son used to beat her black and blue. She couldn't control him.

She said she heard the arguments and understood them but she felt she had no choice but to allow her son to be subjected to these things. That is a big factor for families. When you're at the end of your rope, when your home life, your other children and your health are all suffering and you can't get the support you need, it is very easy for the professional community to convince you that anything they do to that person is right.

We were recently at a conference where one of the presenters pulled out the medical records of one of the people he was treating with intrusive procedures and put them up on an overhead projector for the 300 participants to see. The person's mother was present. She had never had any indication her child was on the amount of drugs shown on the screen. If I were the drug store owner, I would've been driving around in a Cadillac. The mother was afraid. She had never seen these records before and had not given consent for them to be used for the presentation. We as participants were privy to this person's life. You couldn't get the same information on the medical status of test monkeys at the university. They just won't release that kind of information. We were annoyed with the organizers of the conference for allowing this to happen. We were furious with the presenter, who was from a government-run institution, for breaking the government rules on confidentiality just to make a point. We must stop these things. It infuriates us that people think so little of other human beings that they feel it's okay to present their records without consent. The worst part is that we're condoning it by ignoring it and allowing it to happen. It's completely wrong.

We know of a little guy who is in an institution, whose crib is too small. He's in dreadful shape physically. But government inspectors go in on a monthly basis and say it's okay. That's intrusive and aversive.

We were at a conference on autism several years ago. In the reception area, they were playing a videotape showing the "success" of a particular program. I couldn't believe it. There was a young teenager ripping off his clothes, jumping around the room. Then they showed how they handled this with intrusive procedures, then how much he had improved. At the time we were completely horrified. I wondered where the dignity was for this young man not only to be subjected to these treatments but to have it all shown in public.

Not long ago, I heard again about this same institution in Maryland from another person interested in the issue. They had shot ammonia up a child's nose in the name of treatment. There was a major court case after that. Ironically, it was the parents who wanted the place to stay open. They thought it was a good place.

We feel very lucky that the people we've had the good fortune to come into contact with are the people who have the right message. We could've very easily gone the other way, as those other parents did. When you get desperate, you'll do almost anything. There were certainly times when we encountered absolute desperation. We went through nights where our whole kitchen was torn to shreds. Food was thrown out of every cupboard, dishes on the floor — we were desperate. Yet there were people around saying, "It'll be okay." We had each other and two other children so Jeremy was really special to us all. When you love someone, you tolerate a lot. Somehow we managed. It's hard work but we had a lot of support along the way. Unfortunately, there are many other families who don't have support. It seems incredible that in big cities there isn't the support that families desperate for help need.

We know of a mother who was told her son would never walk. She was desperate, confused, but she persisted. Two weeks ago her nineteen-year-old son walked up and down the driveway twice. She showed us pictures of her son from thirteen years ago. He was in an institution uniform, his head was shaved — he looked like he had been in a concentration camp. In reality, it was in this province (Ontario), only thirteen years ago. It was truly incredible. Today, he is wearing the latest jeans, $130 basketball shoes because that's what the other kids in the neighbourhood wear. The gang at the nearby McDonald's had a huge celebration because he learned to walk. Now he can dance in a congo line and do whatever else he chooses to do. And to think he was abused and drugged because of his differences. That young man was lucky because his mother finally said no to the intrusive methods that weren't helping him. She saw that there was an alternative.

What many families don't understand is that support must be built not around themselves but around their family member with a handicap. A life-long network should be put in place to help with advocating. For instance, lawyers who are involved with children with a mental handicap should know the children and be part of the network. Similarly, doctors who care about them should be included. And perhaps most important of all, other teenagers should take part who are going to be around for the next sixty to seventy years to advocate with them and who will give them a boot in the pants now and again to make them smarten up just like our own friends do to us.

Unfortunately, that doesn't happen for most people with a handicap. We know a young man who is eighteen years old. When he left the institution he was in, he hit himself an average of 1000 times a day. Data was collected over a period of six months. When I first met him, I watched people try to cope with him. First you feel sorry for the person. Then when you're there for an eight-hour shift, you get extremely frustrated, and then angry. People were running around him trying to cool his face with wet towels, others were getting him something to drink, they just didn't know what to do next. The part of us that has dealt with Jeremy said, "What is this young man trying to say?" Instead of wasting time collecting data, they could've simply been asking him questions like: "What do you need? Are you comfortable? Would you rather do this or that? I'm feeling this way, how are you feeling?" It sounds simplistic but it took a year of asking those questions and now he doesn't hit himself any more. No drugs, no behaviour management rituals, just simply paying attention to who this individual was as a person. He is a different young man today.

Part of the problem is the setting people live in. If you live in a huge place with other people who have extraordinary behaviours, what you end up with is compounded extraordinary behaviours. We found that out with Jeremy when he was in a special program. He would come home and do things he had never done before. We would ask him who in the program does those things and he would tell us. We would then say, "Do you need to do those things?" Then he would stop.

We know another young woman who has pica. She has an amazing talent. She can pick a thread out of fabric and shread a shirt. The fine motor skills involved in that are incredible. We had heard about this woman before we met her so we thought of bringing her some dull needles, wool and an embroidery hoop. When we met her, we gave her these things. When she began to pull at her blouse, we encouraged her to use the items to embroider. Now her embroidery may not look like a professional's but it's an abstract expression of herself. It helps her to maintain her dignity by keeping her blouse intact. None of that required any sophisticated behaviour modification.

If people start criticizing this common sense approach, we should just turn the argument back on them. We all have idiosyncracies that might bother someone else, but we are not subjected to behaviour modification to stop them. The approach for eliminating head banging, biting, hitting and scratching should be more simple than professionals are making it. Using love, understanding, communication, support networks and a strong belief that the individual is a human being who is attempting to tell us something are really the keys. We find it very sad that we must continually turn around to remind people that they are dealing with human beings. Too often they forget.

Only the "chosen few" realize what is going on behind closed doors. It is this "chosen few" who must gather armies of people to convince politicians that these things are wrong. If we were to take a cattle prod or, if you like, an electric shock prod into the Ontario legislature, Queen's Park, to show a politician what the device is like, we'd be arrested for carrying a weapon. Yet in another government-run building, the prod is being used on human beings who are vulnerable. The frightening part is that it's seen as okay for people who have been segregated or seen as different.

The Jewish people had the misfortune of encountering this over forty years ago at Auschwitz and Dachau. They are making the world listen today. Will it take forty years before someone listens to what is happening to people with a mental handicap who are self-abusive? First it was the simple cattle prod, then it was the cattle prod on a stick to protect the person inflicting the shock and now it's remote control shock. When are we going to stop these hurtful things done in the name of protection?

In a way, they are mistreating parents and staff too. No parent places their child out of choice, but if you make a fuss, they have a lot of power over you. They say if you don't like it you can take your child home. Of course, many parents have no supports at home so that isn't a choice for them. And most parents don't know the loopholes that people like us know of.

The same approach is taken with staff. If the staff person doesn't agree with the program and they object loudly enough, they are transferred to the worst ward. If they don't follow the party line, they are punished. It's simply an issue of control. It is one of the worst power and ego trips you could ever imagine.

There is also a hierarchy of professionals. Those who stray off the accepted procedures are professionally discounted and isolated. If it's not a sophisticated water therapy or sand therapy or play therapy, it's no good.

One of the problems is that the advocacy movement has gotten too "proper." While they've been "proper" by task-forcing and negotiating around the issue, how many times has the cattle prod been used? How many times has time-out been used? How many faces have been sprayed with water or lemon juice? How many children have been restrained? When you're going to attack something you've really got to do it. These things should not be happening and we are condoning them because they are still going on.

We need young people shouting about it, telling other young people. We need to create rage and anger. We have to get off our fannies, stop educating ourselves and start educating those who have no knowledge of what's happening to people with a mental handicap who have self-abusive behaviour. We need some cattle prods and some remote control shock equipment to show people how horrific they are. We need community supports because the community is safer. But most of all, we need to respect the dignity and value of people with handicaps and recognize that they are human beings just like us.

This text was drawn from a conversation held at the Prices home during which Jeremy Price was present. Jeremy was clearly upset by the topic being discussed and many times interupted the conversation shutting off the tape recorder. As a consequence, Margaret Price felt unable to communicate the vigour with which she opposes aversive therapy for fear of further disturbing her son.

6.

Aversive Therapy: A Violation of Human Decency

Dot Ewen

It is hard to believe that we are once again confronted with the issue of aversive therapy, that out there in scattered places of the treatment world there persists an opinion that it is acceptable for those who do not have handicaps to practice violence towards those who do have handicaps to bring their behaviour into line. The question is not a new one. Over the past two decades, the battle has raged. During the early seventies, there was a major trend towards the use of cold showers, wooden spoons, cattle prods and remote shock apparatus, all ostensibly for the care, education and support of children and adults with severe behaviour disorders. Throughout Canada and the United States, people were advised that punishment was the best way to help their offspring and many were trained in the use of the tools of aversive therapy. Painful punishments were being inflicted upon people in the absence of positive reinforcement stategies to support alternative or incompatible behaviour. Much of this "therapy" was being applied by a group of relatively untrained people who called themselves "behaviour therapists." No guidelines were in place. No protection, no rescue was being provided. Few studies of the long-term effects of punishment were being undertaken and the short-term studies were single-subject models. In the absence of acceptable alternatives, many families were forced to place their children in large institutions where self-injurious behaviour tended to increase dramatically during the years, resulting in full restraint for most of the days and nights. Favell et al. demonstrated in 1978, that the full camisole restraints used in institutions were, in fact, acting as positive reinforcement for self-injurious behaviour.[1]

It is hard to believe that in examining where we were, we describe where we are. Could it be that with all the promise of the power of reinforcement strategies, in the final analysis, contingent violence is the best that decades of behavioural studies have produced? Some would have us accept this, but in truth, what these years have produced is valuable information that further dissuades us from relying upon aversive procedures.

In the technical arena, the use of physically punitive strategies is impractical, cumbersome, unacceptable to the public and has not been shown to solve any problems for the person enduring them. Some of the most frequently discussed concerns are:

1. The use of physical punishment models of aggression towards others. The more influential or prestigious an individual, the more likely we are to imitate his/her behaviour.
2. Avoidance behaviours develop. Lying, blaming others, becoming surreptitious or sneaky are common examples.
3. The punisher begins to be perceived as the punishment (conditioned). This interferes with our ability to have a positive relationship with the receiver of the punishment.
4. Punishment is a control technique, not a teaching strategy. Therefore, it is likely that any resulting behavioural change will not persist in other environments and/or in the presence of other people.
5. It is easy to inadvertently punish the wrong behaviour. For example, a child who while apologizing for an infraction of the rules is immediately punished could consider apologizing a punishable behaviour.
6. The research on long-term effects of punishment is sparse and inconclusive.
7. Inficiting pain upon others can be addictive. Because massive violence works in the short term to control others, the punisher is reinforced in his/her behaviour and will rely upon punishment more and more in the future.

8. It is difficult to use physical punishment tactics across environments. You cannot take your cattle prod to the supermarket. Therefore, consistency is difficult unless the individual is extremely isolated. This, of course, leads to the further problem of monitoring and to the question of how isolation exacerbates problem behaviours.

These difficulties were identified early on in the literature and provided significant impetus for the development of positive strategies that are available today. And while these and other negative factors cause most professionals to refuse to employ aversive techniques, there are moral and ethical issues that are even more compelling.

Canadian consensus is well developed in the area of physical punishment. In no other professional jurisdiction do we allow violence to be applied for the control of the behaviour of others. It has been the habit of those ignoring the moral and ethical issues to put forward arguments that seem ridiculous and frightening when applied to any other citizen in the population. The argument most often proffered is that professionals will only use pain when the clients are "a danger to themselves and/or others." Yet this argument has been resoundingly rejected when applied to any other group. We do not use violence as a tactic to change such behaviours in people who are incarcerated because of violent criminal activity. Nor do we use shock as a deterrent against sexual activity by AIDS carriers. Nor do we permit such tactics to be used against aggressive adolescents. Therefore, it is astounding that we are expected to accept this rationale when it is applied to citizens who have a mental handicap.

We are citizens of a society where freedom to choose, to make decisions for ourselves are fundamental expectations. Indeed, we might shake our head in puzzlement when one of our compatriots refuses a medical procedure or declines a blood transfusion, knowing the full potential ramifications of such a choice. Despite our puzzlement, we respect that citizen's right to do so. How ludicrous it seems, to propose that professionals be given the right to overrule such decisions because we as individuals do not know what is best for us.

It has been argued that those with mental handicaps are not capable of exercising choice when, in fact, we know that most have simply not been afforded the opportunity. Despite this, when confronted with attackers using shock, noxious stimuli and other pain-inducing procedures, these people express themselves clearly in many ways. These expressions are summarized and documented in a recent monograph published by the Association for Persons with Severe Handicaps. Outlining a summary of the side effects of punishment, the monograph reports that their responses to the pain inflicted by punitive approaches include, crying, struggling, resisting treatment, trunk twisting, arm flapping, leg extensions, grimacing, spitting, coughing, screaming, wincing, closing eyes, avoidance behaviour, hitting themselves.[2] These are clear expressions of rejection of "treatment" and no matter how deeply we bury our heads in the sand we cannot ignore them.

The use of painful, punitive means to change the behaviour of people with mental handicaps is a violation that is clearly part of a broader injustice. We have allowed ourselves to become accustomed to seeing this segment of the population set aside, treated as a lesser people, dehumanized. Professionals and elected representatives and indeed often family members have been swayed by arguments that are outrageous, arguments that are used daily, and not only on this issue, to attack and isolate these people. Could we accept, for example, that new Canadians to whom English is a second language should be isolated during the educational process?

Would it be good enough to say that these individuals would be happier "with their own kind"; that it is "too expensive" to mainstream them; that they will suffer academically and need "special education" in their own languages; that in the mainstream they would have to suffer the ridicule of others because "they are different"? In fact, as Canadians, we celebrate the varieties of our ethnic groups. We tout the Canadian mosaic and acknowledge the richness that these differences afford. We spend millions in supporting and emphasizing these differences.

We must train our ears to pick up any rationale that creates discomfort for us when applied to other segments of the population. We must expose and resist all of the strange illogical arguments no matter what the issue. Some may be hard to identify, for they are subtle. In this instance, the discrepancy is obvious and blatant.

There can be no justification for the use of pain and violence. We cannot accept it. We must not allow it.

References

1. J.E. Favell, J.F. McGimsey, and M.L. Jones. "The use of physical restraint in the treatment of self-injury and as positive reinforcement" *Journal of Applied Behaviour Analysis*, 1978, 11, 225-241.
2. D. Guess, E. Helmsletter, H. Rutherford Turnbull III, and S. Knowlton, *Use of Aversive Procedures with Persons who are Disabled: An Historical Review and Critical Analysis*. Seattle: The Association for Persons with Severe Handicaps, 1987.

7.

This May Hurt a Bit[1]

Orville Endicott

Section 12 of the Canadian *Charter of Rights and Freedoms* says, "Everyone has the right not to be subjected to any cruel and unusual treatment or punishment." We are fortunate to live in a country that clearly prohibits the use of physical or psychological pain and suffering by agencies of government against any of its citizens. It is staggering to think of the number of the world's nations in which torture is a routine method of maintaining state control over the activities of people whose behaviour is seen as a threat.

But even in Canada, and even with the *Charter* as the law that is supposed to govern those who govern us, there are people who are routinely subjected to pain as a means of forcing them to comply with the expectations of those who have charge of them. At least in Ontario, persons who are identified as developmentally handicapped and who exhibit serious behaviour difficulties have been given electric shocks delivered by means of a device designed for use on livestock. The "Hot-Shot" cattle prod, ironically manufactured in Savage, Minnesota, has been used by the staff of the Southwestern Regional Centre, an institution near Chatham, Ontario, in a program involving several residents who have a history of self-injurious behaviour.

For more than a year, the Ontario Association for Community Living has led a campaign to persuade the Minister of Community and Social Services that he should order a stop to this form of treatment. The Minister, the Honourable John Sweeney, maintains that the shock device is used only when all other methods have failed to prevent the harm these persons do to themselvs. The ministry has prepared standards to guide the use of this and other kinds of aversive treatment. In addition, the minister commissioned the Ontario Research Foundation to develop a new prod specifically for use on humans, and this refined version is apparently now in use. It is supposedly adjustable to administer a weaker or a stronger jolt that is allegedly not as painful as the cattle prod.

When told that no other province in Canada sanctions the use of painful electric shock as a treatment for persons with disordered behaviour, Mr. Sweeney suggested that the authorities in the other provinces lacked the political courage to do what is likely to be regarded unfavourably by the general public, and consequently resort to such means of behaviour control as physical restraint or massive drug dosages to prevent self-injury. But the reluctance to use shock may soon diminish in other provinces because of new developments in the field.

A whole new level of technological sophistication has been achieved by researchers in the United States, who have developed a "shock suit" called the Self-injurious Behaviour Inhibiting System (SIBIS). This device incorporates sensors in a head-band that activate electrodes attached to the wearer's arms or legs. Any extraordinary movements result in an instantaneous shock. The elimination of the necessity of a staff person having to stand there and administer each shock is bound to make SIBIS attractive to those who believe in the efficacy of punishment. The shock suit is also wired to a computer that records the frequency of the unwanted behaviour, thus providing the data to show that it is effective in reducing the frequency of such behaviour. Mental health professionals in Nova Scotia have expressed considerable interest in trying out this new device.

In the spring of 1987, OACL filed a complaint against the Ministry of Community and Social Services with the Ontario Ombudsman, alleging that the use of contingent electric shock (i.e., prodding people when they attempt to hurt themselves or others) violates the *Charter of Rights and Freedoms*, and that alternative treatment models had not been adequately explored and utilized. The Ombudsman agreed to investigate the complaint, but has recently stopped the investigation in response to the ministry's decision to invite OACL to appoint representatives to sit on a Task Force on Research to Identify Alternatives to the Use of Contingent Shock. Under the Ontario Ombudsman Act an investigation may be put on hold while steps are being taken that may lead to a resolution of the matter complained of.

The Ontario Task Force will have to address some very serious quesitons, including the following:

1. Does contingent shock do what its proponents claim it does?

It is my understanding that the data on the effectiveness of shock as a means of controlling self-injurious behaviour are inconclusive. The frequency of the unwanted behaviour tends to diminish, but there are reports that tell of the recurrence of the problem once the shocks are no longer applied. Tim Stainton, formerly of the OACL staff, has an explanation for this phenomenon: people who have been hurting themselves tend not to do so while someone else is doing it for them, but after the external punishment stops, they go back to their former pattern.

Self-injurious behaviour may indeed by only a part of a lifelong pattern of punishment. Patrick Worth, President of People First of Ontario, spoke very convincingly on this subject at the CACL National Conference in Halifax in November 1987. He maintains that for many people who are labelled mentally handicapped, life consists of one punitive experience after another from early childhood on. If the punishment does not primarily consist of the infliction of physical pain, it may well be found in the experiences of isolation, segregation and rejection. Hearing him speak, I could not help wondering how anyone could possibly suggest that a solution to the difficult behaviours sometimes manifested by such persons is to administer yet more punishment. Indeed, I think an argument can be made that even if punishment "works" in terms of reducing the frequency of destructive behaviour, it simply cannot work in terms of enabling the person to have human relationships that affirm his or her value and dignity, and to have a reason to want to behave cooperatively and productively.

2. Are less punitive aversive techniques more acceptable?

There is an extensive arsenal of punishments historically and currently in use with persons identified as exhibiting problem behaviour. Most of these are less grotesque and less physically painful than cattle prods. They include social isolation (the so-called time-out rooms), physical restraint, verbal abuse, deprivation of food or of other less basic necessities or pleasures, and exposure to stimuli that are unpleasant to any of the five senses. Although it may be less objectionable to use measures that cause less acute pain, it is CACL's position that punishment should never be employed as part of any program for controlling the maladaptive behaviour of persons who have suffered all their lives as a consequence of being labelled mentally handicapped.

Deliberate, programmed punishment is unacceptable because it undercuts the factor that is most likely to lead to permanent freedom from serious destructive behaviour, namely bonding based on affection and trust between one human being and another.

3. Are there effective non-punitive approaches to severe behaviour problems?

There is evidence that self-injurious behaviour or behaviour that threatens the safety of others can be brought under control by a person who is treated kindly, respectfully, and in a way that establishes participation and interaction (in other words, friendship) between that person and another. I suppose the strongest and most consistent evidence is that which Jean Vanier, founder of the l'Arche movement, has shown us for decades. Can anyone imagine a circumstance that would cause him to reach for the cattle prod? In the context of the current dispute over the use of aversive procedures, John McGee of Omaha and Herb Lovett of Boston, among others, have demonstrated how effective positive approaches can be.

4. Is it lawful to shock people or to subject them to other noxious stimuli to stop their destructive behaviour?

We began by reciting the constitutional right set out in section 12 of the Canadian *Charter of Rights and Freedoms* not to be subjected to any cruel and unusual treatment or punishment. What does this mean, and how can it be protected? Since the *Charter* came into effect in 1982, most of the judicial interpretation of section 12 has been in the context of the punishment of those convicted of criminal offences. The courts have ruled that such punishment is "cruel and unusual" when it is so excessive, in proportion to the seriousness of the crime, that it shocks the conscience and offends contemporary standards of decency. Some judges have taken the view that, in spite of the fact that the section prohibits both treatment *and* punshiment that are cruel and unusual, it only applies to the punishment of criminals. The American *Bill of Rights* speaks only about punishment. The addition of the word "treatment" in the *Charter* should, one would think, create a somewhat broader scope.

I think it is arguable that certain kinds of aversive treatment for the correction of behaviour disorders do violate the *Charter*. The courts could be asked to rule specifically on this question and to order such practices stopped if it is found they constitute cruel and unusual treatment. The fact that there are non-aversive ways of dealing with the same problem should accentuate the cruelty and unusualness of using shock.

Aside from the *Charter*, it may be an offence under the *Criminal Code of Canada* to inflict electric shock or other aversive stimuli on another person, even in the guise of treatment. If you touch anyone or even physically threaten to do so, without the person's express or implied consent, you have committed an assault. If you touch someone with a cattle prod that delivers a painful shock on contact, and that person has not consented to allow you to do so, no one would doubt that this would be a criminal assault. In the context of the use of such measures on persons having problem behaviours, it seems unlikely that any of those persons have consented. Any substitute consent given by a parent or guardian would, in my view, be invalid. In the the *Eve* case, the Supreme Court of Canada ruled that substitute consent is only valid for procedures that are necessary for the sake of the health of the person who lacks the capacity to give his or her own informed consent. From the evidence we now have, the use of aversive techniques is clearly unnecessary for the control of destructive behaviour.

Necessity is also a defence in itself against a criminal charge. If you can present evidence that, had you not committed the act with which you are charged, something worse would have happened, then you are likely to be acquitted. Can those who use cattle prods or other devices to hurt persons with behaviour problems say that in the absence of such treatment these persons would have done more serious harm to themselves? Perhaps so. Before rejecting such a defence, the court would have to hear irrefutable evidence that there are highly effective, non-punitive ways of preventing self-injurious behaviour.

American courts have refused to order the cessation of aversive interventions. The agencies defending such practices have been able to convince the judges that they had established standards and guidelines for deciding when it is appropriate to resort to punishment, and that it should be left to their professional judgment to decide how to deal with problem behaviour. The courts like to find some middle ground between the positions of the disputing parties. The use of aversive interventions is naturally repugnant, but if there are elaborate safeguards and review committees, then the courts may feel some sense of assurance that there will not be flagrant abuses. But this is a matter where there really is no middle ground. It makes no sense to say that we will try positive approaches, and if they don't work, then we will use aversive approaches. Could you forge a healing, restoring friendship with a person while carrying a cattle prod in your pocket, just in case?

Note

1. This article is reprinted from *entourage* (1988), vol. 3 (2), 13-17.

8.

"The Therapy of Despair": A Family Medicine Perspective

Yves Talbot, M.D.

Over the last few years, a shift in services for people with a mental handicap has begun between institutions and the community. Family physicians, as community-based practitioners, are becoming increasingly involved in services for people with mental handicaps in their communities either through their own practices or because of their involvement in group homes in their neighbourhoods.

When people's behaviour is deemed unacceptable for the individual or the community, physicians can be called upon to assist in the behavioural treatment. Whether this involves the use of restraints for elderly patients labelled "senile" living in nursing homes, or the use of physical or chemical aversive procedures on people with a mental handicap, physicians are consulted in discussions about the management of their self-injurious or socially disturbing behaviours.

Ideally, the family physician will not only attempt to treat the behaviour, but will adhere to the philosophy of family medicine. Practitioners are encouraged to explain people's behaviour not only as a response to their disability but as a reaction to environmental and social factors (i.e., workplace, living arrangements, education, family and peer group).

Even more importantly, the family physician is expected to follow the paradigm of family medicine that states:

> The family physician is educated and trained to develop and bring to bear in practice unique attitudes and skills which qualify him or her to provide continuing, comprehensive health maintenance and medical care to the entire family regardless of sex, age or type of problem, be it biological, behavioral or social. The physician serves as the patient or family's advocate in all health related matters, including the appropriate use of consultants in community resources.
>
> *(American Academy of Family Physicians, 1975)*

If strictly adhered to, this paradigm makes the best interest of the patient paramount to the physician, thereby preventing any unnecessarily harsh procedures for behavioural treatment.

Physicians are involved in long-term relationships with their patients, which enables them to acquire extensive, intimate knowledge of the lives and values of patients they see regularly. It is this long-term knowledge that often helps them understand why someone may present a specific problem. Too often, people with handicaps are seen by health professionals with only episodic frequency. The lack of continuity in caregiving is often reflected in the long lists of medications administered to the patient in an attempt to pacify not only the patient but also the attending staff. Resorting to these chemical "treatments" may reflect a lack of commitment to the patient on the part of the physicians.

A strong commitment to the patient as a person is a vital component in family medicine. The mark of good general practitioners is their overriding interest in patients as people. Good physicians are devoted to the individuals whatever the problem may be because their commitment is to people more than to knowledge or to a branch of technology. Very often in such a relationship there is not a clear distinction between medical and non-medical problems. Family physicians cannot avoid problems of life, they either cultivate their skills to manage disease and illness, or they realize their limitations and decide to seek out other sources of help.

But there is a danger when these limitations are realized and when patients with challenging behaviours are referred to behaviour "specialists" who may put the patient at risk of being "treated" with aversive procedures.

In this case, physicians must abide by the philosophy of the "honest broker." Physicians accept the responsibility for their patient's total health care. Although family physicians may not have the expertise to manage all problems, they must act as coordinators for the various health intervenors (i.e., neurologists, psychologists and surgeons) on their patient's behalf.

Family medicine is now embracing a broader conception of health and disease. A major shift has occurred in the paradigm of general medicine. The limitations of the "germ theory," which searches for the medical causes of illness, are now understood. A multiplicity of factors, both organic and non-organic, are included in the explanation of the occurrence of a specific problem. Even if the concept of a more systemic view is not new in some areas of medicine, it is only recently that it has reached a broader appeal amongst the practitioners of family medicine. Although many traditional general practitioners add an acute sensitivity to the context of the patient's problems, it is only recently that trained family physicians have been exposed to social and behavioural sciences in psychotherapy and family therapy in their residency training. In addition, the systemic/biopsychosocial approach is intellectually attractive to many family physicians who have worked with patients long enough to feel the limitation of the biomedical model.

After several years of practice, family physicians see many patients with chronic conditions returning with ill-defined medical complaints. Repeated unsuccessful attempts to solve these problems with the biomedical approach often force the physicians to search for alternative solutions. At the same time, the recent competitive, cost-conscious environment of medicine has led to a recognition that examining a patient's context (for example the stress of the family situation) can save money if the physician does not use high-tech methods of evaluation. Similar factors must be taken into consideration with individuals living in group homes or institutional environments. This could avoid the use of medication or restraints altogether.

But still, certain situations generate helplessness and hopelessness in the caregiver. Last resort therapies enter at this point. Even medication is not immune to them.

Aversion therapy includes techniques designed to reduce unwanted or "dangerous" behaviour. These methods are commonly applied in treating obesity, tobacco smoking, obsessive oral habits, aberrant sexual behaviour, self-injurious and aggressive behaviour and substance abuse.

Most of the strategies imply that behaviours are learned and aversion is one re-educational method that can be used to extinguish an unwanted response. These strategies are based on a very traditional understanding of behaviour that associates stimulus and response. They do not take into consideration any elements of the context that could be important in causing the behaviour.

Although there has been some interesting and enthusiastic research on aversive techniques, specifically with smoking, drinking and even self-injurious behaviour, the studies were often very poorly controlled as either single or group case studies. On the other hand, controlled studies have often pointed to the equal efficacy of the non-aversive techniques or the strengths of the placebo effect.

It is interesting to notice that in the context of specific medical entities, aversion therapy remains very much a solution of last resort. For any physician, problems of obesity, smoking or drinking have to be the most frustrating and difficult clinical challenges. Because of their frustration, physicians often seem either to ignore or lecture patients who are seen as abusing their own health. Physicians feel helpless and, in their desire to help, they become susceptible to the use of any potentially helpful solution no matter how painful the treatment may be (i.e., the use of emetic for drinking problems). I cannot help but think that there may be a small element of revenge in using these methods. The physician feels forced into using this "therapy of despair."

Be that as it may, it is clear that in many circumstances social changes in the individual's environment or support groups (i.e., Overeaters Anonymous, Alcoholics Anonymous or Smoke-Enders) have a major role to play in facilitating behavioural change. These forms of social intervention, which make use of positive reinforcement, are strategies much more in tune with the philosophy of family medicine.

Advocates of aversive therapy have often used the medical model (particularly surgery) to justify the necessity of pain for healing patients. It is important to realize, however, that pain is not a treatment in itself (as it is thought to be in aversive therapy) but only a side effect of the treatment. Pain is not a therapy.

Current pain management strategies minimize the painful side effects of treatment because a decrease in pain is believed to accelerate the rehabilitation process. In the areas of treatment and diagnosis, medicine has made a major effort to use the least invasive procedure. For example, ultrasound is now used instead of dyes; CAT scanners instead of exploratory surgery; and non-surgical removal of gallstones and kidney stones instead of surgery.

Most patients can express their preference for the least invasive procedures and will critically question aversive procedures when their application is recommended. These patients are able to demand alternatives on their own behalf.

Children and adults with an intellectual handicap present a challenge to physicians since most of the decisions regarding their treatment are made by a third party. In these cases, family physicians often act as translators for patients and their families, interpreting the modalities of treatment suggested by consultants. Particularly in cases where aversive procedures have been suggested, the physician must take on the role of "patient broker" to ensure that all alternatives are explored and explained to patients and their families.

Family medicine must concentrate on seeing challenging behaviours not only as genetic or learned but also as the result of a specific context. Intervention aimed specifically at changing the individual's behaviour without taking into account changes in the individual's environment is not only likely to fail but is highly unethical when applied without informed consent.

Community-based physicians involved in decision making for patients with a mental handicap must make good use of their understanding of behaviour to raise the question of whether the environment is not in part responsible for the patient's self-injurious behaviour. But as brokers and advocates, family physicians must more than simply question the use of aversion, they must actively promote the search for and use of non-aversive alternatives.

Living in the Community: Stephen

Jill Leach

Stephen eyed me nervously as I walked up behind him. He stood rigid, ready to spring should I come too close. "Hi, Stephen," I said. "Did you see all the boats out there?" I pointed to the sailboats and cargo ships in the harbour. Stephen momentarily turned toward the boats but quickly diverted his gaze back to me. I smiled at him as I joined the staff who'd accompanied us on this walk.

"When Stephen first moved into the community, he wouldn't make eye contact with anybody. He wouldn't let anyone touch him either. He's really opened up to others recently. He looks right at people now and will even accept hugs from those he's familiar with. In fact, a couple of times he has offered hugs of his own," commented one staff person.

Unlike most people who grow up in institutions without parental participation, a great deal is known about Stephen's background. There is a history of highly educated and ambitious people in Stephen's family. His mother was a nurse and his father, a commercial pilot. Unmarried, and unable to cope on her own, Stephen's mother took him to an institution when he was two years old. While he was considered unmanageable, there appears to be no indication of any developmental delay at that point.

When Stephen was seven, he was diagnosed as having a condition called PKU. PKU is a congenital inability to digest a protein found in milk. Treatable with accurate diagnosis at birth and appropriate diet before age ten, the developmental difficulties that accompany PKU can be prevented. All babies are now automatically tested for PKU at birth, but Stephen was born prior to the universal application of this procedure.

Untreated, PKU causes irreversible mental deterioration, leading to a diagnosis of "profoundly retarded." Considered uneducable, many people diagnosed as having PKU have simply been left to wait out their existence. No real attempt was made to encourage any kind of growth in Stephen once he was diagnosed.

While he may not have been educated, and does not speak, Stephen is acutely aware of everything that goes on around him. He fully comprehends what people say to him and his perception is obvious.

In the institution, where Stephen spent most of his life, he was considered highly self-abusive. As with his housemate Barry, Stephen was drugged continuously in an effort to control his potentially dangerous behaviours.

I sensed an underlying volatility to Stephen and, at about 178 cm. tall, he would not be easy to control physically. Drugged to a vegetative state as he was, he would prove to be considerably less of a problem for staff in the institution.

Stephen was full of nervous energy as we walked. Always ahead of us, he seemed to want to run and jump at life. Yet no matter how quickly he outdistanced us, he always kept us in sight, periodically looking over his shoulder to place our position behind him.

Stephen's enjoyment on the walk appeared to come from the physical activity. Unlike Barry, who was absorbed in his surroundings and derived pleasure from his observations, Stephen seemed to be motivated by the speed of his own movement. I sensed a natural leader in him; he liked to be at the head of the group, ensuring he was always first as we wove our way along the seawall.

Victim of a cruel joke in the institution, Stephen now suffers from a severe nicotine addiction. While the specific motivation may never be identified, it is well documented throughout institutions that some staff would make a game of throwing cigarettes on the floor, watching residents dive for them and eat them. Not understanding the inappropriateness of such behaviour and, perhaps, responding to the laughter and approval of staff, many institutionalized men and women grew up repeating this ritual whenever possible.

Ingestion of nicotine through the digestive tract is far more serious than smoking. Stephen was particularly affected by this and became obsessively focused on the search for cigarette butts. His activities outside the institution were revoked and Stephen became a prisoner in his world as a result.

Locked in his ward, as protection against his maladaptive behaviour and addiction, Stephen began to display increasingly self-abusive behaviours. Documentation at the institution clearly indicated that his hyperactivity and self-abuse began well after his institutionalization. Prohibited from participation in normalized community living, Stephen's role models became controlling staff and other institution residents who, like Stephen, were locked away from the world, severely drugged and repeatedly restrained. Records show that Stephen's behaviour patterns were identical to his roommates at the institution.

When frustrated or angry, Stephen would bang his forehead against the nearest flat object. He would run across the barren floor of the common room of his ward and slam his body against the large windows at one side of the room, or he would rock his body back and forth in his chair, stopping just short of smashing his head against the marble floor. Sometimes he would miscalculate the distance.

Uncontrollable and out of control, Stephen was caught in a systematic and repetitive cycle of banging and self-abuse that was always countered with physical restraints and escalating drug dispensation.

Now, in his own home drugs are not used as a control mechanism with Stephen. Rather, he is encouraged to develop personal restraint — to check his own behaviour and modify it until appropriate. After nearly three years of community living, and at thirty-one years of age, Stephen is finally responding to the concept of self-control.

This has not been easy for either Stephen or the staff who work for him. After twenty-six years of modelling inappropriate and maladaptive behaviours, it has been difficult for him to adapt to and accept the expectations and rewards of society.

Stephen's slamming into walls and windows as a tool for recognition or an outlet for frustration and anger was an immediate concern for staff. Furniture was arranged in ways to block the open spaces he needed to build up momentum as he threw himself against standing structures. Extra thick drywall, heavy drapes or wooden shutters on glass windows and fabric decorations were used to diminish Stephen's destructive effect when he was out of control. Quilted and padded pictures on the walls decreased the opportunity for damage to both him and the house.

The furniture placement is no longer an issue as Stephen has stopped throwing himself against windows and walls. Some doors, which provide yet another flat surface to pound on, will soon be replaced with curtains.

These preventive and creative approaches not only remove opportunities for Stephen to be self-abusive, but do so in a non-punitive manner. He is not being forced to repress self-destructive and maladaptive behaviours because he is controlled by another power. He is learning to adapt and grow as a person through self-respect and self-control. Through non-threatening means and consistent interaction with people who are able to take the time he needs, he is learning to make choices in his own life.

His nicotine addiction is managed with a nicotine gum substitute prescribed by a doctor and administered appropriately. No one smokes in Stephen's house and it has been discovered that if he is busy he will often forget about the gum.

Stephen is still self-absorbed, but no longer continuously abusive as he was in the institution. He is becoming more comfortable with the process of socialization and includes people in his life now. As he develops his own non-threatening persona, Stephen seems more willing to open up his life to others and share what he has to offer of himself.

From close and constant attention, a major shift in expectations and abundant support, Stephen has changed from someone who has total disregard for other people and property to a man developing a sense of self and ownership who can tolerate close co-existence with others.

Stephen is currently in a day program where he learns life skills to assist him in assuming responsibility for his actions and his own care. His nervous energy is diverted into constructive physical activity and he works hard delivering flyers in his neighbourhood.

There is optimism and enthusiasm about Stephen's future from the people who know him best. He continues to learn and grow, relying less frequently on old destructive behaviours. Instead, they are replaced with choices, rooted in self-respect and awareness of the consequences of his behaviour that have a beneficial effect.

As one staff person said, "Punitive behavioural modification techniques inhibit personal growth and potential. They achieve nothing beneficial in the long run. All they prove is a failure to figure out how to communicate with the individual who is subjected to them — a fast fix based on controlling people."

I think of Stephen and the decades of spiralling self-abuse that were never addressed, simply controlled or repressed by drugs. I think of how, in less than three years, he has managed to significantly decrease those negative responses. The contrast between the institutional and community approaches to Stephen's behaviour is stark and disturbing. Finally having the opportunity for options similar to those not labelled mentally handicapped, Stephen is shining as he flies into the new experiences his life offers.

9.
Legal Advocacy and the Use of Aversives

Brian Weagant and Dorothy M. Griffiths

A small number of people with developmental handicaps engage in behaviours that are severely self-injurious or aggressive. Many behavioural practitioners believe that the "treatment" of choice in such situations is a technique called an "intrusive procedure." The milder forms of such techniques include things such as temporary arm restraint or isolating the person from any positive form of reinforcement (such as human contact). Should the mildy intrusive techniques prove to be ineffective in controlling the behaviours, many behavioural psychologists would turn to aversive stimulation as a way of temporarily suppressing the offending behaviour so that more "positive" programming can be brought in. The aversive techniques that are most common in these situations include: mechanical restraint, noxious stimulation by taste (lemon juice, tobacco), noxious stimulation by smell (ammonia, smelling salts), noxious stimulation by loud noises (white noise, fog horns, shouting), application of water spray, force feeding and contingent electric shock (faradic stimulation).

There are other practitioners who believe there are effective non-aversive alternatives to aversive stimulation, even in the most difficult of cases. This group of practitioners feels it is unethical to proceed with an aversive when there are gentle and equally effective alternatives.

Currently, both schools of behaviourism are practised in Canada and the profession continues to debate the efficacy and ethics of the use of aversives. But it is more than just a clinical debate: there are legal ramifications and considerations that must be considered by both the legal advocates for people with developmental handicaps and by the practitioners. This chapter will explore several legal avenues that might be taken by lawyers and legal advocates who propose to challenge the use of aversives on people with developmental handicaps.

The focus here will be on the aversive known as contingent electric shock. It is a technique that is seen by some to be more intrusive than the other aversives "in that the affected treatment levels are likely to be acutely painful rather than merely uncomfortable or unpleasant."[1] Although the following arguments might be raised against any of the aversives, the procedure most likely to attract judicial intervention is contingent electric shock. If successful, a precedent would be set for attacking other less extreme forms of aversive stimulation.

The authors premise the following arguments on a fact situation involving a person who is, *practically or in law*, "incompetent" to refuse the aversive. It is assumed that all questions relating to competency have been addressed first.

The legal advocate acting on behalf of an "incompetent" person being subjected to the aversive can proceed, not from a position of vested interest, but from the logical position that the client would refuse the aversive if he/she could. By definition, an aversive is something an individual would avoid if the individual could.[2]

This chapter will discuss three legal arguments that can be advanced against the non-voluntary use of contingent electric shock for purposes of behaviour modification. These arguments are:

I. that the use of such a technique is proscribed by section 12 of the *Charter of Rights and Freedoms* ("Everyone has the right not to be subjected to any cruel and unusual treatment or punishment").

II. that sufficient consent could never be obtained for such a technique because it is not a therapeutic procedure (the principle in the case of *Eve*);[3] and

III. that section 7 of the *Charter*, which guarantees that everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice, would proscribe such a technique because it is not the least restrictive course of action available, and because its use may be nothing more than punishment.

The arguments below are mere outlines: they are not blueprints for challenges, nor are they comprehensive constitutional law analyses. We shall raise the legal issues and in so doing, demonstrate how a legal challenge might be mounted.

I. Cruel and Unusual Treatment or Punishment

The Canadian *Charter of Rights and Freedoms* should prove to be a useful tool in the hands of legal advocates challenging the use of certain types of "therapeutic" activity.[4] A *Charter* challenge involves a two-stage process. First, the applicant must establish on the balance of probabilities that an act of government has directly, or indirectly, through its effect,[5] violated the *Charter* right of an individual. Then, the party seeking to uphold the violation must demonstrate that the violation (or "limit") can be reasonably justified. Fundamental to a *Charter* attack is that there must be something done by government, or pursuant to statute, that can be attacked. In our fact situation, someone is proposing to consent to an aversive on behalf of an incompetent person. That substitute decision maker must draw his/her/its authority from either statute or the common law. Only where the treatment authority flows from statute can the *Charter* be invoked.[6] Therefore, decisions made on behalf of adults by committees (pursuant to the *Mental Incompetency Act)* could be challenged by attacking the legislation purporting to give such power.

Section 12 of the *Charter* provides that everyone has the right not to be subjected to any cruel and unusual treatment or punishment. There has been little judicial consideration of what this right encompasses. Almost all reported decisions have dealt with punishment or disposition in a criminal context. The exact scope of the word "treatment" in this guarantee as applied to problem behaviour that is not criminal is judicially undetermined.

The American judiciary is prepared to give an expansive meaning to the words "cruel and unusual punishment" when interpreting American constitutional guarantees. The case of *Welsch v. Likins*[7] involved a class action by six residents with developmental handicaps of various Minnesota mental health facilities regarding treatment and conditions in the hospitals. The Court held (among other things) that the constitutional stricture against cruel and unusual punishment is not restricted solely to particular kinds of punishment, but also applies to mere confinement to an institution that is characterized by conditions and practices so bad as to be shocking to the conscience of reasonably civilized people.

The American Eighth Amendment only proscribes cruel and unusual punishment. The Canadian *Charter* guarantee encompasses both treatment and punishment. One can easily speculate, then, that if institutional "practices" are embraced by the American stricture, "treatment or punishment" will receive at least an equal interpretation by our Courts.[8]

What might constitute cruel and unusual treatment? What would be the elements of a test? Unfortunately, we can only look to the various tests developed in criminal case law. The best statement of the various factors or components of a test that might be considered can be found in the case of *R. v. Langevin*.[9] Making the necessary changes for the focus of this discussion, the following might be considered:

1. Is the treatment such that it goes beyond what is necessary to achieve a legitimate treatment aim?
2. Is the treatment such that it has no value in the sense of some therapeutic purpose? Is it punishment or rehabilitation?
3. Is the treatment unnecessary because there are adequate alternatives?
4. Is the treatment unacceptable to a large segment of the population?
5. Is the treatment such that it cannot be applied upon a rational basis in accordance with ascertained or ascertainable standards?
6. Is the treatment in accord with public standards of decency or propriety?
7. Is the treatment unusually severe and hence degrading to human dignity and worth?

The Court was silent on what weight was to be given to individual components of the test. Thus, it is open to creative argument as to when a section 12 infringement crystallizes.

These criteria could be argued using evidence of clinical practice. Two of the criteria deserve mention here.

Alternatives to contingent shock do exist (criterion three), but their adequacy and availability in a specific situation are dependent upon expertise and resources.[10] However, it is now generally conceded in the profession that alternatives can and do exist.

Another critical element of the *Langevin* test is the consideration of whether the procedure can be conducted within the standards of practice created by psychologists and sanctioned by the governing bodies. In many cases, it appears the answer is "no." The decision to use contingent shock often comes at a crisis point where, because of emergency, the examination of less restrictive alternatives or the existence of the proper clinical environmental conditions become moot considerations. In such cases, the use of contingent shock has bypassed the systematic process of clinical review, as the standards of the profession would dictate.

Assuming that one has passed the first stage in the process, that is, a court has been convinced that the use of contingent electric shock passes the test of "cruel and unusual," then the court will engage in a scrutiny of the possible justifications for infringment of the right. This is done pursuant to section 1 of the *Charter*. That section reads:

> The *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.

We will not enter into an analysis of section 1 (*Charter*) case law. The Supreme Court of Canada set out a detailed analysis of what is required under section 1 of the *Charter* in the case of *R.v.Oakes.*[11]

Briefly, the party seeking to allow contingent shock would be bound to prove that the objective served by the existence of such form of "treatment" is of sufficient importance to override the constitutional right. Second, the party trying to uphold the use of the aversive would have to show that the objective and means chosen to advance it (a) are carefully designed to achieve the objective in question, (b) impair as little as possible the right not to be subjected to such treatment and (c) must be proportional to the effects of allowing such treatment.

If the thrust of the case for the applicant is simply that an alternative must be chosen as the course of treatment, then the fact of the existence of a less restrictive course may be the entire focus of the section 1 argument. If it can be shown that the positive alternative was never tried in earnest, then the state cannot justify impairing the section 12 rights of anyone, especially when it is treatment and not punishment that is in issue.[12]

II. "Eve" and the Sufficiency of the Consent

The Supreme Court of Canada rendered a judgment in the case of *Eve* on October 23, 1986.[13] In a unanimous decision, the Court held that it would not rely on its *parens patriae* jurisdiction to order a non-therapeutic sterilization for someone who was unable to consent to or refuse the procedure. In the absence of the affected person's consent, it can never be safely determined that non-therapeutic sterilization would be for the benefit of that person. Although the decision in the case is confined to the facts in *Eve*, the judgement implies that a third party cannot ever consent to any non-therapeutic procedure.[14]

The issue is simply this: although the practitioner has the parent (in the case of a child) or the committee (in the case of an adult) willing to give consent to the aversive procedure, is the consent *sufficient* in law for such a procedure? The answer depends on whether aversives in general or in the particular circumstances of a case can be characterized as therapeutic or non-therapeutic and whether the aversive in question is clearly necessary for the sake of the person's well-being.

Simply because a procedure offers relief from a problem does not necessarily make it therapeutic. This matter was dealt with by Mr. Justice Wood in the case of *Re K.*, a decision of the Supreme Court of British Columbia, released January 31, 1985. That was a case where the mother of a child with a severe handicap asked the court to sanction her decision to have a hysterectomy performed on her daughter. There was evidence that the daughter had anxiety and phobic reactions to the sight of her own blood. Her mother sought the hysterectomy to prevent the onset of menses. Mr. Justice Wood indicated that the decision would be less complex if the proposed treatment were therapeutic. However, it was decided that in the case of a non-therapeutic procedure, a rigorous test must be passed by the third party proposing the treatment.

The Court launched into a discussion of the treatment to ascertain if it truly was therapeutic or not. Medical opinion was called and it was divided. One doctor was of the opinion that the operation could not be considered therapeutic because it would not treat an existing illness. Other doctors took a broader view of the concept of treatment. The Court took note of the report of the Law Reform Commission of Canada, Working Paper No. 26 (1980):

> Although the notion of therapeutic and non-therapeutic is broadly invoked in medical practice, the difference in fact between them is often obscured ... There is no ready solution to the overlapping borders of treatment and non-therapeutic interventions. Decisions should be made on a case-by-case basis.

The Court went on to find that whether or not a procedure would be classified as therapeutic involves consideration of a number of factors, including a balance of the potential risks and benefits. He went on to find that since the hysterectomy was being proposed to counter future anxiety, the procedure could not be regarded as therapeutic. The Court was cognizant of a plan proposed by the trustee wherein a desensitization program could be designed to help the child overcome her fear of blood. Under the circumstances, the mother's application was denied.

This decision was subsequently overturned by the Court of Appeal of British Columbia.[15] That Court indicated that the matter must be decided using the "best interests of the child test" and felt the distinction between therapeutic and non-therapeutic was of little relevance.[16]

There is a case to be made that faradic stimulation, or contingent electric shock, is nothing more than punishment and, therefore, cannot be considered "treatment" at all. If it is punishment and not treatment, then it is not therapeutic.

The psychology profession uses the term "punishment" to refer to many of its techniques. Ontario's *Behavioural Standards*[17] refer to contingent electric shock as,

> a *punishment procedure* in which an aversive electrical stimulus is briefly applied (e.g., to the bare skin of the leg or forearm for a one-second duration) immediately following the occurrence of a predefined response, with the goal of decreasing the future probability of that response. (Emphasis added)

This concession by the psychological profession begs the following question: can a punishment technique be considered therapeutic? It can be argued that a therapeutic procedure is something quite different from a punishment procedure in that the two procedures have quite different goals. The psychologist Edward Carr referred to the use of aversive approaches, such as contingent electric shock, as *crisis management*; therapeutic intervention, in contrast, is the replacement skill building that is conducted to provide the individual with a functional alternative for the maladaptive behaviour.[18]

Given this reasoning, it is argued that in the absence of the informed consent of an individual, a third party could never be in a position to give substitute consent for a procedure that is of doubtful therapeutic nature. For the same reason, and because of the presence of alternatives, neither would the Court be in a position to allow a procedure to which an individual would, arguably, not consent (if in a position to so do).

III. Security of the Person and the Right to Treatment

A *Charter* argument could also be raised using section 7:

> Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

It is generally agreed that this section guaranteeing the right to security of the person would cover a punishing behavioural technique.[19]

It is still early in the development of the judicial interpretation of our constitution. The precise nature of the guarantees in section 7 are still a matter of legal conjecture. One important doctrine developed under the comparable American constitutional guarantee, the Fourteenth Amendment's "due process" guarantee, has been the "right to treatment" doctrine. A synopsis of a leading case in the area will conveniently summarize the doctrine.

Wyatt v. Stickney[20] was a class action brought against three Alabama facilities for people with mental handicaps. Alabama had the worst spending record per patient in the entire United States. All the residents involved in the action had been civilly committed.[21] The Court held that "the purpose of involuntary hospitalization for treatment purposes is treatment and not mere custodial care or punishment ... To deprive any citizen of his or her liberty upon the altruistic theory that the confinement is for humane, therapeutic reasons and then fail to provide adequate treatment violates the very fundamentals of due process."

Lower American courts have expanded and used this doctrine in various ways: due process requires that a state place persons committed for a mental illness in the least restrictive setting available consistent with legitimate safety, care and treatment objectives.[22] Where treatment in a hospital is more restrictive of liberty than treatment in community-based facilities, the failure to provide the latter constitutes a deprivation of liberty in violation of the Fourteenth Amendment.[23] In *Welsch v. Likins*, noted above, the court held that certain practices, such as physically restraining for control without first attempting less restrictive measures may have infringed the rights of the patients.

The Supreme Court of the United States has been quite conservative in its interpretation of the "due process" clause and what it means to persons civilly committed in terms of their treatment. Although it has not specifically rejected the notion of "the least restrictive alternative," it has resisted making a finding that such a right is entrenched in the American Constitution. All the Court seems to have done is confirmed that civilly committed persons have a right of access to a basic level of habilitative treatment. Even the extent of that right is unclear. The response has been that all but three legislatures in the United States have enacted mental health legislation limiting state action.[24] The Supreme Court of the United States has said, in an earlier pronouncement unrelated to mental health law, that

> even though the governmental purpose be legitimate and substantial, that purpose cannot be pursued by means that broadly stifle fundamental personal liberties when the end

> can be more narrowly achieved. The breadth of legislative abridgment must be viewed in the light of less drastic means for achieving the same basic purpose.[25]

In Ontario, services rendered pursuant to the *Child and Family Services Act (1984)* are subject to the stated purpose in section 1 of the Act that "the least restrictive or disruptive course of action that is available and is appropriate ... should be followed."[26] The principle must be applied in concert with other stated principles and all are subject to the paramount objective, which is to promote the best interests, protection and well-being of children.[27]

For adults who are having decisions made by a third party, there is no legislation that insists that the least restrictive alternative is a guiding principle in substitute decison making.

Section 7 of the Canadian *Charter* is more expansive than its American counterpart. There are indications that the "right to treatment doctrine" will work its way into our law. Certainly, the legislative trend seems to be that the "least restrictive alternative" aspect of the doctrine is an idea whose time has come.

In the recently decided case of *Philip Joseph Grady v. The A.G. for the Province of Ontario et al.*, a decision of the Supreme Court of Ontario, handed down 12 January 1988, Mr. Justice Callaghan restates the basic "right to treatment" doctrine without ever defining it and without any reference to the *Charter*. That case involved a habeas corpus application brought by Mr. Grady. Mr. Grady was on a Lieutenant Governor's warrant after having been found to be not guilty by reason of insanity of an indictable offence. Following a warrant hearing, he was transferred to the secure treatment centre at Penetanguishene from Brockville Psychiatric Hospital apparently for no reason that had been raised at the warrant hearing. The Court found that the transfer to Penetanguishene was counterproductive from a treatment point of view. There he received no treatment and had no psychiatrist. The Court found that this was tantamount to a denial of liberty.

> Except in the unlikely event that he is discharged absolutely by the Lieutenant Governor under s. 545(l)(b) of the *Criminal Code* without a supporting recommendation from the Board, Mr. Grady will be deprived of complete liberty until he is pronounced "recovered." Thus his right to liberty,

> given our current assumptions about treatment of mental illness, hinges on his access to treatment for his illness. A denial of treatment might be reasonably justified if there was evidence of a need to protect the public which could not be met at Brockville, but that is not the case here. In effect, therefore, to the extent that he is denied treatment opportunities, he is indirectly deprived of liberty.

Mr. Justice Callaghan is saying that if one's liberty rights are restricted, then one must be given the treatment opportunity one needs to end that restriction.

How can this be of aid in an argument concerning aversives? The gist of one argument is this: if we are going to use these techniques on an unwilling individual (liberty infringement), then the individual must also be given access to whatever eventual treatment is needed to be free from the aversive (regain his/her liberty). If that "other" treatment is not available, or if the patient is not amenable to the other treatment, then the use of the aversive is nothing more than punishment, a mere symptom suppressor, and contrary to section 7 of the *Charter*.

Contingent electric shock in itself is a means to a very limited end. It is a behaviour suppressor. Theoretically, once the behaviour is gone, that aspect of the "treatment" is finished. Many recipients of aversives are candidates for more aversive therapy very soon after the original application, and many have to be maintained on programs that include the continuing use of aversives. In short, many recipients are never truly free from the aversive — they never regain their liberty. In such cases, it could be argued that the technique should never have been employed in the first place.

As argued above, contingent electric shock is a form of crisis management. In isolation, neither shock nor the other aversives can be said to be treatments that purport to end restrictive procedures. It is other programmatic elements drawn from the patient's environment that eliminate the use of restrictive and intrusive procedures. Elements such as an enriched environment, habilitative programming to replace the function of the inappropriate behaviour and careful promotion of generalization and maintenance are the true factors that free the individual from the restrictive setting.

If there is success in persuading a Court that there has been a violation of the guarantee of security of the person, the Court would then review the legislative authority permitting the intrusion against the principles of fundamental justice. The principles of fundamental justice are found elsewhere in the enumerated guarantees in the *Charter* and also in the basic tenets of our legal system.[28] Put simply, does the legal authority to consent to such "treatment" on behalf of someone else, a "treatment" that compromises an individual's right to security of the person, accord with the fundamental freedoms laid down in our Constitution?

Obviously, it can be argued that such authority effectively contravenes another section of the *Charter* (the right not to be subjected to cruel and unusual punishment) and also contravenes a constitutionally protected "right to treatment." It is also arguable that the right to treatment embraces the principle of the least restrictive form of treatment and that there are alternatives to the aversives.

As outlined above, a *Charter* challenge also involves a discussion of section 1 of the *Charter*: one party may wish to defend the law that allows the section 7 violation. Once again, if the existence of effective alternatives has been proven, then the law that permits the use of the aversive alternative could not be saved under section 1, as there is another way of achieving the objective of the law without restricting the section 7 rights of the individual.

Conclusion

In this chapter, we have explored three possible legal arguments that might be raised to stop the use of a particular aversive therapy (contingent electric shock) on an unconsenting individual. The three approaches are not discrete and a real legal challenge would involve the interplay of all the issues raised here.

Of course, there are other possible legal approaches. For example, the *Criminal Code* may ultimately prove to be the vehicle for judicial scrutiny.

What is essential is that both practitioners and lawyers see the role the law may play in the controversy over the use of aversives. Legal advocates will be playing a central part. On this point, the closing words from Mr. Justice La Forest of the Supreme Court in the case of *Eve* deserve some attention:

In conducting these procedures, it is obvious that a court must proceed with extreme caution, otherwise, as MacDonald J. noted, it would open the way for abuse of the mentally incompetent. In particular, in any such proceedings, it is essential that the mentally incompetent have independent representation.

Notes

1. *Standards for the Use of Behavioural Training and Treatment Procedures in Settings for Developmentally Handicapped Persons*, Ontario Ministry of Community and Social Services (January, 1987).
2. Aversiveness is defined by the degree to which someone would avoid its use. See, *Report of the Professional Advisory Board Steering Committee*, Ontario Ministry of Community and Social Services, September, 1986, at page 62.
3. *Re Eve*, [1986] 2 S.C.R. 388, 31 D.L.R. (4th) 1.
4. See H. Archibald Kaiser, Electroconvulsive Therapy as "Cruel and Unusual Treatment or Punishment," *Health Law in Canada* (1986), vol. 7, No. 2.
5. In *R. v. Morgentaler, Smoling and Scott* (1988), 31 C.R.R. 1, S.C.C., Chief Justice Dickson says (at 25) that even "if the purpose of legislation is unobjectionable, the administrative procedures created by law to bring that purpose into operation may produce unconstitutional effects, and the legislation should then be struck down." The door seems open to challenge that acts of a committee of the person, not because the *Mental Incompetency Act* violates the *Charter*, but because the administration of the power conferred pursuant to the *Act* has an unconstitutional effect.
6. See *Retail, Wholesale and Department Store Union, Local 580 et al. v. Dolphin Delivery et al.* (1986), 25 C.R.R. 321, S.C.C. This judgement seems to settle the question of the applicability of the *Charter* to the common law. Parents acting on the common law right to consent /refuse aversive treatment for their children would not be subject to *Charter* strictures. Thus, private arrangements in Ontario for children (with a private psychologist, for example) would not be subject to *Charter* scrutiny, whereas

arrangements made with government-licensed service providers would be so subject (because of *Child and Family Service Act* regulation of the procedures used by those service providers.

7. *Welsch v. Likins*,C.A. Minn. 550 F.2d 1122 (1974).
8. See H.A. Kaiser, supra.
9. (1984), 9 C.R.R. 16 (Ont. C.A.).
10. Availability and cost are definitely relevant to any justification argument (section 1 of the *Charter*; see below) in that they have been specifically rejected as grounds. Madam Justice Wilson said in *Singh et al. and the Minister of Employment and Immigration*, 14 C.R.R. 13, [1985] 1, that *Charter* guarantees would be illusory if they could be ignored because it was administratively convenient to do so. The question arises, however, what role do availability and cost play in assessing whether there are alternatives in a "cruel and unusual" argument.
11. (1986), 24 C.C.C. (3d) 321 (S.C.C.).
12. For a more scholarly analysis of section 1 and treatment, see H.A. Kaiser, supra, footnote 4.
13. *Re Eve*, [1986] 2 S.C.R. 388, 31 D.L.R. (4th) 1.
14. See Margaret A. Sommerville, "Therapeutic and Non-Therapeutic Medical procedures — What Are the Distinctions?" *Health Law in Canada*, (1981), Vol. 2., No. 4, 85.
15. *Re K. and Public Trustee* (1985), 19 D.L.R. (4th) 255, B.C.C.A.
16. Mr. Justice Wood seems to have been vindicated, indirectly, by the decision in *Eve*. Further, the Supreme Court (not sitting in appeal of *Re K.*) said that the decision of the Court of Appeal "is at best dangerously close to the limits of the permissible."
17. Supra, footnote 2, at page 87.
18. E. Carr, "Severe Behaviour Disorders," given at the International Research Conference on the Mental Health Aspects of Mental Retardation, Chicago, June, 1987.
19. In *Morgentaler*, supra footnote 6, Madam Justice Wilson confirms that "security of the person" under s. 7 of the *Charter* "protects both the physical and psychological integrity of the individual. State enforced medical or surgical treatment comes readily to mind as an obvious invasion of physical integrity." Thus, even if the procedure is characterized as "treatment," it can still be scrutinized under s. 7.

26. A.M. Donnellan, P.L. Mirenda, A. Mesaros and L.L. Fassbender, "Analyzing the Communicative Functions of Aberrant Behavior," *Journal of Association for Persons with Severe Handicaps*, 9:3 (Fall, 1984).
27. *Community Integration Project, A Description of the Characteristics of Integrated Community-based Programs for People with Challenging Behaviors* (Syracuse: Center on Human Policy, Syracuse University, 1986); see also, Steven Taylor, Julie A. Racino, James A. Knoll, Zana Lutfiyya, *The Nonrestrictive Environment: On Community Integration for People with the Most Severe Disabilities* (Syracuse: Human Policy Press, 1987), 84-5.
28. R.H. Dickey, C. Crawford, B. Salisbury, *Service Brokerage: Individual Empowerment and Social Service Accountability* (Toronto: The G. Allan Roeher Institute, 1987).
29. John O'Brien, "A Guide to Personal Futures Planning," in G. Thomas Bellamy and Barbara Wilcox (eds.), *The Activities Catalogue: A Community Programming Guide for Youth and Adults with Severe Disabilities* (Baltimore: Paul H. Brookes Publishing Co., 1987).

Riketts, Done E. Williams, Mark Mason and Mary T. Stark, "Treatment Strategies for Self-Injurious Behaviour in a Large Service-Delivery Network," *American Journal of Mental Deficiency*, 91:4 (January,1987): 339.

12. R.M. Foxx, M.J. McMorrow, R.G. Bittle, D.R. Bechtel, "The Successful Treatment of a Dually-Diagnosed Deaf Man's Aggression with a Program that Included Contingent Electric Shock," *Behaviour Therapy*, 17 (Fall,1986):173.
13. For an excellent discussion of the moral, ethical and legal aspects of the use of aversive procedures, see Turnbull et al. cited above.
14. Decision of the Supreme Court of Canada, *Re Eve* [1986] 2 S.C.R. 388, 31 D.L.R. (4th) 1.
15. Foxx et al., 173-4.
16. Guess (a) et al., 34-5.
17. Lovaas, cited in Guess (a) et al., 34.
18. John J. McGee, Frank J. Menolascino, Daniel C. Hobbs, Paul E. Menousek, *Gentle Teaching: A Non-Aversive Approach to Helping Persons with Mental Retardation* (New York: Human Sciences Press, 1987), 113-4.
19. McGee et al., 34-9.
20. Turnbull et al,, 192.
21. Turnbull et al., 185-6.
22. Foxx et al.
23. Foxx et al., 174.
24. Guess (a) et al., 31.
25. See Evans and Meyer, *An Educative Approach to Behavior Problems: A Practical Decision Model for Interventions with Severely Disabled Learners* (Baltimore: Paul H. Brookes, 1985); Herbert Lovett, *Cognitive Counselling and Persons with Special Needs: Adapting Approaches to the Social Context* (New York: Praeger Publishers, 1985); G.W. LaVigna and A.M. Donnellan, *Alternatives to Punishment: Solving Behavior Problems with Non-Aversive Strategies* (New York: Irvington Press, 1987); McGee et al. as cited above.

10.

Aversives: Differential "Treatment" for People with a Mental Handicap

S. Dulcie McCallum

One of the most invasive methods of suppressing self-injurious and aggressive behaviour in institutionalized people who are mentally handicapped is the electric prod, known to professionals as a "faradic stimulator." Members of the institutional population in Canada who receive this procedure do not consent to its use. There is no statutory authority that *specifically* empowers parents, institutional administrators or public trustees/official guardians to consent to the use of aversive techniques on behalf of a child or a person deemed incompetent (for whatever reason).[1] Nor, however, are there any *Criminal Code* provisions that *specifically* protect those who administer aversive procedures, the "abusers."[2] Still the practice continues. Those administering the punishment continue to rely on a consent that may be less than legally satisfactory. However, there are a variety of legal sources that the perpetrators will seek to rely upon as "law." These vary from medical consents to common law rights of parents, from child welfare protection legislation to guardianship statutes, and so on. Whether or not these provide any actual authority for the use of an aversive is questionable. In addition, whether or not these laws provide equal protection or benefit for those who are mentally handicapped in this situation is an issue that must be addressed.

What are analogous situations where an aversive technique could conceivably be utilized to suppress a challenging behaviour? The proponents of aversive techniques recommend their use for self-destructive or aggressive behaviour. Examples of self-abusive behaviours among the general population are alcoholism, drug abuse and cigarette smoking. Examples of aggressive behaviour are sexual assault, child abuse, common assault and murder. The use of an electric prod to "treat" an alcoholic, a smoker or a child molester conjures up images of torture unlikely to be tolerated by the public or to withstand a *Charter* challenge to such a dehumanizing technique.

Children or adults with handicaps in the civil care and custody of the state are there by legislative authority, often parental consent, and their status is subject to review by a superior court under its *parens patriae* jurisdiction.[3] In the case of adults, the probable authority for institutionalization, when there is any, is a committeeship order to manage property. It is likely that the courts will question whether or not this provides authority to use an electric prod.[4] Regardless of the reason for the institutionalization of a person and regardless of the nature of that person's aberrant behaviour, the only group of people subjected to aversives are those who are diagnosed as "mentally retarded, developmentally delayed, or intellectually impaired." Though it is difficult to have confirmed officially, it is suggested that there are no examples in Ontario, or indeed in the whole of Canada, where the electric prod is used on any population of children or adults who are not labelled mentally or intellectually impaired. There are, on the other hand, many children and adults with similar challenging behaviours who are not being treated with the electric prod but are instead being cared for with such methods as "gentle teaching."[5]

A thoughtful article by B. Weagant and D. Griffiths[6] explores aversives in the light of section 7 of the *Charter*, which guarantees the right to life, liberty and security of the person, and section 12, which protects a person from cruel and unusual punishment and treatment. The authors explore the therapeutic versus non-therapeutic distinction in discussing the test for third-party consent to this so-called treatment. The equality rights section (section 15) of the Canadian *Charter of Rights and Freedoms* raises another issue with regard to aversive procedures being used solely on people who are mentally handicapped.

In Ontario, the *Child and Family Services Act, 1984*[7] defines "intrusive procedure" as:

(i) a mechanical means of controlling behaviour,
(ii) an aversive stimulation technique, or
(iii) any other procedure that is prescribed as an intrusive procedure.[8]

Arguably, this definition contemplates the other examples cited as aversives and will receive broad interpretation. In Part VI of the *Act*, a process is outlined that permits the minister of community and social services to establish, operate, maintain or approve programs for treatment, but only for children.[9] A court order is required for commitment to a secure treatment program.[10] Prior ministerial approval is required for a service provider to administer psychotropic drugs and intrusives.[11] The *Act* concedes that the legislation is designed:

1. to cover *only* treatment programs *for children with a mental disorder* that is defined as "a substantial disorder of emotional processes, thought or cognition which grossly impairs a person's capacity to make reasoned judgements";[12] and
2. only for programs that "impose continuous *restrictions ... on the liberty* of the children."[13] (Emphasis added)

Remarkably, only a few of the sections in this part have been proclaimed and these do not include the sections that authorize and govern the use of "faradic stimulation." For purposes of our discussion, the only relevant proclaimed sections are section 108, the interpretation section; sections 120-122, dealing with secure isolation; section 123, which establishes an interdisciplinary review team to consider the use by service providers of intrusive procedures authorized by the minister under section 124 (although section 124 is not yet proclaimed); and sections 127-129, which outline additional functions for the review team and the role of the Professional Advisory Board. Despite the fact that the empowering sections having been proclaimed, the review team and the Professional Advisory Board have not been appointed. A recent request of the Clerk of the Legislative Assembly confirmed that no Orders-in-Council have been signed in 1988 to proclaim any further sections in this Part.[14]

The reality of the situation is that the use of aversives by therapists working in government-operated and funded facilities is not being approved under this legislation though the mechanism for doing so has been on the "books" for over four years. Though no legislation requires it, the person seeking to use the electric prod is required *de facto* to apply to the minister. The latter, relying on the professional advice of an appointed council, always reviews a situation prior to authorizing the use of the electric prod. It is generally accepted that it cannot be used without ministerial permission, often obtained through his or her deputy. Scrutinizing the administrative practices of the minister is more difficult if the practices are not in accordance with a statute, especially one that appears to be vulnerable to a challenge under the *Charter*. One cannot help but be cynical, therefore, about why the legislation has not been proclaimed.

It is important to note in this analysis that the minister's overreliance on *medical* professionals in deciding when to use aversives, and the adoption of that model in the legislation, perpetuates the dominance of medical persons in decisions affecting people with an intellectual impairment. The decision to use an electric prod on a child or an adult is one that is predominantly legal and ethical. It ought to be treated as such by those in a position to approve (and any legislation purporting to authorize) its use.

Whether or not the legislation is proclaimed at the time a challenge to the use of aversives is launched, it is suggested that the practice of prodding people who are mentally handicapped and who have challenging behaviours infringes the equality section of the *Charter*. Section 15 has not been judicially interpreted by the Supreme Court of Canada at the time of writing.[15] However, a brief consideration of the kind of argument that might be advanced to the Court in such a challenge is as follows.

Section 15 of the *Charter* states:

> Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on ... mental or physical disability.

This section is designed to protect the rights of traditionally disadvantaged groups. Treatment in the past of those considered mentally handicapped made them a logical and appropriate category of persons to be specifically protected by section 15.[16] For particular conduct to be governed by the *Charter*, it must be authorized, condoned or controlled by government. At this time, the specifics of how the use of electric prods is managed by the minister and his or her department officials are uncertain. There can be no doubt that their use within state facilities is sanctioned by the government and as such is subject to review under the *Charter*. The wording of the section in the constitution dictating the application of the *Charter* states:

> This Charter applies ... (b) to the legislature and government of each province in respect of all matters within the authority of the legislature of each province.[17]

Constitutional authority over hospitals, health professionals and institutional standards has long been considered to fall within provincial jurisdiction.[18] The matter under review need not be legislation but may be the conduct of government departments, representatives and officials.[19]

There can be little doubt that use of the electric prod on this restricted, labelled population demonstrates unequal protection and benefit before and under the law based on mental disability. Though evidence of people with equally destructive behaviour who are not given similiar treatment could be put before a court to accentuate the discriminating nature of this conduct, it is strongly suggested that this approach is unnecessary. To require the existence of a comparable group to establish a distinction based on "mental disability" is to ignore the reality of past and present legislative and societal prejudice. Avoiding that inquiry may also assist the court in resisting the misguided "similarly situated" test. The flaw in that test has been noted by the Ontario Court of Appeal when it said:

> It is not always clear whether persons *are* or *are not* similarly situated, and whether, even if they are not, this is relevant to a section 15 inquiry ... It is usually possible to find differences between classes of persons and, on the basis of these differences, conclude that the persons are not similarly situated. However, what are perceived to be "differences" between

> persons or classes of persons could be the result of stereotypes based on existing inequalities which the equality provisions of the *Charter* are designed to eliminate, not perpetuate.[20]

It is strongly urged that no defense can be found in evidence demonstrating that all persons who are mentally handicapped with challenging behaviours receive this abuse. To permit such a defense under section 15 would ignore the reality of past discrimination and beg the fundamental question underlying the inequality.

What is essential in this analysis is to consider the section 15 argument in light of the violation of other sections of the *Charter*, in this case sections 7 and 12 specifically.[21] The *Charter* is intended to be read as listing specific rights and freedoms and as embodying a value structure gleaned from a reading of the whole.[22] Where a particular legal right such as section 7 (life, liberty or security of the person) is denied, and the denial is done on the basis of an enumerated ground, such as mental disability, then an infringement of section 15 crystallizes. Worded another way, a *prima facie* case is established under section 15 where an individual is denied his or her right to liberty and security of the person by being assaulted with the electric prod, and that denial resulted from the person being labelled mentally handicapped.

The prominence of section 15 and the interrelationship between rights and freedoms in the whole of the *Charter* cannot be ignored. It is not enough to discover a *prima facie* case of a legal right or a guaranteed freedom. The impact on the involvement of other sections will greatly enhance a constitutional challenge. This enhancing quality of the rights and freedoms throughout the *Charter* is reflected in the comments by Madam Justice Bertha Wilson in the *Morgentaler* case where she stated:

> I believe, therefore, that a deprivation of the section 7 right which has the effect of infringing a right guaranteed elsewhere in the *Charter*, cannot be in accordance with the principles of fundamental justice.[23]

A complimentary argument can also be advanced. Where any section of the *Charter* is infringed, there is a *prima facie* case of unequal benefit or protection before or under the law as indicated in section 15. The law in this case is that found in sections 7 or 12 of the *Charter*. Where unequal treatment under those sections is made on the basis of an ennumerated ground, the onus on the applicant is satisfied. This is in addition to any argument advanced against the "law" being the impugned legislation or government action initiating the inquiry into the inequality.

In the case involving aversives, the section 7 challenge advanced in Weagant and Griffiths's article can be conclusively determined because their use also offends sections 12 and 15. The involvement of other sections of the *Charter* means the conduct does not accord with the principles of fundamental justice. Similarly, when the infringement of sections 7 and 12 involves people who fall within a category of persons, such as those with a mental handicap, it will automatically constitute a section 15 infringement.

Can the proponents of this punishment find a successful defense to the infringements of sections 7, 12 and 15 in section 1 of the Charter? That section provides:

> The Canadian *Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.

If the court accepts that a *prima facie* case has been established that to use an electric prod on an institutionalized person who is mentally handicapped is contrary to any or all of sections 7, 12 and 15, the onus would be on the government to justify the practice. The Supreme Court of Canada has consistently applied the *R. v. Oakes* two-pronged test under section 1:

> 1. the objective which the legislation is designed to achieve must relate to concerns which are pressing and substantial; and
> 2. the means chosen must be proportional to the objective sought to be achieved.[21]

Three components to the second part of the test, that of the proportional relationship, have been identified:

> First, the measures adopted must be carefully designed to achieve the objective in question. They must not be arbitrary, unfair or based on irrational considerations. In short, they must be rationally connected to the objective. Second, the means, even if rationally connected to the objective in the first sense, should impair as "little as possible" the right or freedom

> in question ... Third, there must be a proportionality between the effects of the measures which are responsible for limiting the *Charter* right or freedom, and the objective which has been identified as of "sufficient importance."[25]

It is submitted that there is no legal authority for the use of any aversive. It is submitted that for the government to authorize such conduct would require very specific statutory language. Section 1 requires that any limit placed on a right or rights under the *Charter* must be prescribed by law. That requirement is not met. If the legislation in Ontario is proclaimed in due course, then it may qualify as such but only in the case of children. It would then be the impugned legislation under review. In the absence of such a legislative framework, the Court may still be convinced that the state has the authority to consent to such procedures on behalf of children or persons deemed incompetent in their care. This is unlikely, as was previously discussed. Even if that is the case, however, it is submitted that the test in *Oakes* cannot be met. That test will require those seeking to justify this practice to demonstrate:

1. that the limits being placed on the right to security of the person, the right not be subjected to cruel and unusal punishment and the right to the equal benefit and protection before and under the law are reasonable. To make out the test of reasonableness, it is suggested that the state will have to show that the use of an electric prod is not punishment, that it is a treatment, that it is the treatment of choice, that it is a treatment of last resort and that it is the least restrictive and least invasive alternative of the treatments available;
2. that the extent to which the individual's rights are being infringed is as little as possible. A person's right to be inviolable and free from assault is unquestioned.[26] The electric prod involves a repeated, frequent electrical shock. Given the fact that there are very few institutions and therapists who use the electric prod and given that there are successful alternatives that do not involve punishment or physical abuse, the likelihood that the effect of this procedure can be minimized to meet this portion of the test is nil; and
3. that the end justifies the means. There can be little doubt that to

> assist people with challenging needs to discard difficult behaviours, particularly those that are self-abusive, is an important objective. However, in doing so, it is essential to avoid using a method that continues to perpetuate the age-old attitude that persons who are mentally handicapped are devalued individuals entitled to something less than those who are not mentally handicapped. It is important to recognize that these individuals are entitled to a therapy that does not merely replace one painful experience with another with no long-term benefits. The medical community has managed to convince some governments that the electric prod "treatment" has some legitimacy and ought to be condoned and approved. To permit the medical community to use this type of technique on a population historically held hostage by therapists sets a dangerous precedent and leaves open the possibility of attitudinal regression.[27]

People who are mentally handicapped are on the threshold of being recognized for the contribution they make to society. The extent to which that contribution has been recognized and respected to date, however, is marginal. Through the deinstitutionalization movement, people previously restricted to large, locked, segregated settings are moving into the community. While it is recognized that the closure of these facilities cannot take place over night, in the interim, humane treatment must be provided to those awaiting release. It is imperative that the use of aversives, particularly the electric prod and the technologically advanced "big brother weapon" known as SIBIS (Self-Injurious Behaviour Inhibiting System), most easily described as headphones containing an electric shock system, be denounced and discontinued.

Only through immediate government action can a *Charter* challenge be avoided. This differential treatment based on a label can no longer be tolerated. It would be difficult to conceive of a more blatant example of a discrepancy in how we treat a particular group of people based on an ennumerated, prohibited ground. It serves as a prime example of the objective underlying the proclamation of the equality rights section of the *Charter*.

In the end, if the courts are invited to enjoin the state from approving the use of aversives, when the electric prod strikes, the *Charter* will light up like a Christmas tree.

NOTES

1. The only possible exception is the guardianship legislation in Alberta; *Dependent Adults Act*, R.S.A. 1980, c D-32. The reason is that court orders under that Act must specify each power granted to the Committee. If the order is silent regarding the use of aversives, presumably the person acting as a committee does not have the authority to consent to their use.
2. Charges of common assault can be laid against those using the electric prod. The availability of a defense under s. 43 of the *Canadian Criminal Code* has all but been obliterated by the case of *Ogg-Moss v. The Queen* (1985), 6 C.H.R.R. D/2498 (S.C.C.). In that case, a mental retardation counsellor was charged with common assault for hitting one of his chargees. He invoked a defense that as a mental retardation counsellor he stood in the shoes of a parent and that an adult with a mental handicap could be viewed as a child, entitling him to use force by way of correction. The court rejected this defense. Though the court restricts its comments to assault in the context of correction and witholds comment where assault is for self-defense or treatment, it is adamant that:

   > One of the key rights in our society is the individual's right to be free from unconsented invasions on his or her physical security or dignity and it is a central purpose of the criminal law to protect members of society from such invasions (at p. D/2502).

   It would be for the accused to demonstrate authority to perpetrate the assault as a treatment. Neither could reliance be placed on s. 45 of the *Criminal Code*, which protects physicians in situations involving surgery only. See: *Morgentaler v. The Queen*, [1976] 1 S.C.R. 616, at p. 644.
3. For discussion of *parens patriae* for adults, refer to *Re Eve*, [1986] 2 S.C.R. 388; for children, refer to *In Re S.D. (Stephen Dawson)* (1983), 43 B.C.L.R. 173 (S.C.).
4. The *Eve* case did not involve the *Charter*. However, it is important to recall that the Supreme Court of Canada was not prepared to empower a Committee appointed under guardianship legislation to authorize a non-therapeutic sterilization of a

woman who was mentally handicapped. Where a public official has care and control of an institutionalized person, do they, by virtue of an administrative certificate, property order, or medical consent have the authority to consent to a technique that is as invasive and demoralizing as the use of the electric prod and that may not consitute a treatment?

5. "Gentle teaching" is a non-aversive approach to caring for people with mental handicaps. John McGee is coauthor of *Gentle Teaching: A Non-Aversive Approach to Helping Persons with Mental Retardation* (Human Sciences Press: New York, 1987) and offers a series of training seminars and workshops throughout the year and across Canada in cooperation with The G. Allan Roeher Institute. His workshops are designed to teach non-aversive approaches to dealing with challenging behaviours.
6. Brian Weagant and Dorothy M. Griffiths, "Legal Advocacy and the Use of Aversives," supra, chapter 9.
7. *Child and Family Services Act, 1984,* Stats. Ont. 1984, c. 55, as amended.
8. Ibid., s. 108(b).
9. Ibid., ss. 109(1)(a) and (b).
10. Ibid., s. 110.
11. Ibid., intrusive procedures ss. 124-125; psychotropic drugs s. 126.
12. Ibid., s. 108(c) "mental disorder."
13. Ibid., s. 109(1).
14. Contact made with the Clerk at the Legislative Assembly in Toronto on Friday September 30, 1988.
15. The case of *Andrews v. The Law Society of British Columbia*, an appeal from the B.C.C.A., has now been heard by the Supreme Court of Canada but remains undecided. It will be the first opportunity for the S.C.C. to interpret s. 15.
16. For examples of an historical perspective of the kind of treatment and abuse suffered by the mentally handicapped see: Law Reform Commission of Canada, "Sterilization: Working Paper 24," (Ottawa, 1979); *Re Eve*, supra, footnote 3; Harvey G. Simmons, "From Asylum to Welfare," (National Institute of Mental Retardation, 1982); and John P. Radford and Allison Tipper, "Starcross: Out of the Mainstream," (The G. Allan Roeher

Institute, 1988).

17. The Canadian *Charter of Rights and Freedoms*, s. 32(1)(b).
18. *British North America Acts*, 1892, s. 92; For general discussion see: P. Hogg, "Constitutional Law of Canada," (1977); For a recent case dealing with health in a constitutional context see: *Winterhaven Stables Ltd. v. Attorney General of Canada* (1986), 71 A.R. 1 (Q.B.), at p. 15.
19. Anne F. Bayefsky, "Defining Equality Rights," in *Equality Rights and the Canadian Charter of Rights and Freedoms*, edited by Bayefsky and Eberts, (Toronto, 1985), c. 1. For an example of the lengths to which the courts are prepared to scrutinize the practices of government in the absence of a legislation being under attack, see *Operation Dismantle v. The Queen* (1985), 18 D.L.R. (4th) 481 (S.C.C.).
20. *Century 21 Ramos Realty Inc. v. The Queen* (1987), 58 O.R. (2d) 737 (C.A.).
21. For details of ss. 7 and 12 arguments related to aversives see supra, footnote 5.
22. *Lyons v. The Queen*, [1987] 2 S.C.R. 309.
23. *Morgentaler v. The Queen* (1988), 31 C.R.R. 1 (S.C.C.).
24. *R. v. Oakes*, [1986] 1 S.C.R. 103.
25. Ibid., at p. 139.
26. Supra, footnote 1.
27. For a discussion about the electric prod and alternatives, see Orville Endicott, "This May Hurt a Bit," supra, chapter 7.

Living in the Community: Barry

Jill Leach

I met Barry and Stephen at the beach on a mild February Sunday in Vancouver. We walked the seawall from Kits Point, where the mountains border the inlet and ships rest in port, to the centre of the city at the Granville Island Market. On Sunday, the beach is alive with strolling families, joggers, and dogs that run freely along the shoreline. The market bursts with the sounds of trade, street performers and an intricate, steady stream of cars.

As we talked, my mind drifted to the thought of an institutionalized Barry and the riveting contrast to his current lifestyle. Barry spent the first four years of his life with a family on a farm in Peace River. He still speaks of cows and horses and it's obvious that his memories of that time are vivid and frequent. He began life surrounded by open spaces, with the rhythms of farming and the freedom brought by an unencumbered lifestyle.

An aging photograph shows a bright-eyed and beautiful child. To gaze at the picture is to witness an aware and intelligent expression. Even now, at forty-seven, his eyes are startling with their clarity and lack of malice. He was quietly happy as we walked, absorbed in observation and only stopping to delight in the dogs that passed us by.

There is a gentleness to Barry that pulled at me. People who know him talk of his mild, happy-go-lucky personality, but I was unprepared for the calm he exudes. During our walk, I had the sense that he was at peace with himself and his world. And as we walked, I found myself relaxing as well, being drawn into his contentment.

No one knows what happened to Barry's natural parents, who they were, or where they came from. Institutional records show he spent his first four years with foster parents, but many details are missing. Barry's past is locked in the memories of those who may no longer be living. His early life is expressed only by his own references to farm animals.

At four years of age, for reasons that were not recorded, Barry was admitted to an institution by his foster parents. For the next forty-three years, he moved several times between the two largest institutions for people with a mental handicap in the province at that time.

Barry is a slight person, and at about 157 cm. tall gives a fragile impression. Lacking an imposing physical stature, Barry was frequently the object of violence by other institutional residents. Powerless to defend himself against the anger and aggression of others, unable to coherently verbalize his personal horrors, he sought the only release available to him: self-abuse.

An escalating pattern of self-abuse emerges, increasing in both frequency and intensity. Barry's story is not atypical of people who've grown up in institutions. Unspoken childhood rages evidenced by incessant rocking of their bodies or general lack of cooperation with the systems that control them, evolve into striking out at others or inflicting pain upon themselves.

By virtue of having lived in an institution and an inability to speak fluently, Barry was denied both a forum for appropriate expression and recourse for the abuse he suffered at the will of others. His only avenue for power or control over the events in his life seemed to be through self-abusive means. His self-abusive behaviours became tools for ensuring input into the direction of his life.

It can be difficult for those of us who have grown up in communities to understand that there is any rationale behind self-abusive behaviours. Superficially, self-abuse appears to be the fulfillment of a need to hurt oneself and is nonsensical in the logic of "normal" living.

However, a simple twist of perspective reveals the pathos of survival in an institution. Total dependence upon a system that had no room for individuality robbed a passive person such as Barry of any opportunity to appropriately exercise personal power and self-direction.

Not only did Barry bear the brunt of physical abuse, certain behaviours he displayed in the institutions suggest he suffered sexual abuse as well.

Barry began by scratching his face, increasing the frequency and severity of his injuries as he grew older. By the time he was thirty, permanent scars evidenced the damage and he began displaying other forms of self-abuse. He would vomit at will. At night, in bed, he would probe his internal organs causing massive blood loss and leading to chronic anemia from the frequency.

Barry's self-abuse was the one thing in his life that defied total control. It was the only thing no one could completely take away from him. Growing up on wards with no privacy or free will, no personal possessions to speak of, and little affection or attention, Barry's self-abuse was the only thing he truly owned and it was the tool that brought staff, many staff, running to him specifically.

Barry's disturbing behaviours became life-threatening and his medications were increased to control his impulse to self-abuse. At one institution, Barry and Stephen lived on the same ward. The common area of this particular ward was a large room with grey-green plastic benches lining two walls and a television held high in a cabinet at one end of the room. The centre of the floor was open and barren. However, there were large windows on one side of the room. People would sit on those benches watching TV or staring out windows. Self-abuse was common here.

Behaviour management consisted of *pro re nata* (as needed) orders for a variety of psychotropic drugs. Whenever Barry became agitated or gouged at his face, those drugs were administered until he settled down. Through random and massive administration of drugs he spent years at the institution, stupefied and powerless for the most part.

Life on the ward was repetitious, pointless and emotionally impoverished. No consistent attempt was made to teach age-appropriate behaviours. Understaffed and overworked, ward staff emphasized control of behaviours to ensure manageability of residents.

In the institutions, Barry's self-abusive behaviours were allowed until they became problematic to staff. Records show no indication that the source of his self-abuse was directly addressed or investigated.

Three years ago, at the age of forty-four, Barry moved into a house in a middle-income neighbourhood near Vancouver with Stephen and one other young man. Their home is one where personal ownership and responsibility are stressed by staff.

"Of all three, Barry seems to have suffered the greatest damage from institutional living," says one staff member.

"The transition to the community was most difficult for Barry. Having lived in institutions for over forty years, he didn't understand or trust the conditions offered by community living. He wasn't sure how to respond to the privacy of having his own room or the relaxed structure he has in his own home."

Consequently, the past three years have often been unsettling and challenging for Barry. After four decades of continuous sedation, it becomes extremely difficult to learn new ways of behaving. With greatly reduced medication and an emphasis on personal accomplishments, growth and independence, Barry has been thrust into a culture that had become foreign to him. Adaptation to these new expectations has been slow for him and there continue to be setbacks from time to time, but change occurs steadily.

He is no longer focused on self-abusive behaviours. Less damaging ones remain, but continue to decrease as Barry becomes more comfortable with his new autonomy. The drastic and life-threatening behaviours have disappeared completely.

Once relegated to a locked ward because he could not be counted on to behave appropriately in public, Barry now participates in his community, and every Tuesday night goes to a movie with a staff member. A man of discerning tastes, Barry decidedly prefers westerns, musicals and horror films.

He is fully involved with maintenance of his home and has equal responsibility with the others for housework and meal preparation.

"Barry loves music and cooking. He'll hum away and sing while he does his work around the house," says a staff member.

However, after years of regimented living conditions and denial of individual needs and growth, Barry is upset easily by changes in his routine.

Through the staff's philosophy of emphasizing personal responsibility and growth, combined with a steady decrease in the medications he takes, Barry now periodically expresses an intense anger that screams out in contrast to his usual easy-going nature.

I asked several staff how they cope with Barry's self-abuse and bursts of temper, and I found a very "normalized" approach. Barry is expected to assume responsibility for himself and his actions. He now understands cause and effect and the consequences of choices in the same way anyone living in the community does.

"Whenever Barry would be self-abusive we would show him that the act had no effect on staff. We didn't use any special treatment (positive or negative) when he was self-abusive. As much as we could we ignored his behaviour and, in effect, took the power and impact out of it."

In institutions, Barry had been able to use his self-abuse to get special attention and sympathy. He was able to manipulate staff to spend more time with him, and during periods where he damaged internal organs, profuse blood loss would bring attention by doctors and nurses as well. A trip, even to the hospital, broke the mindless continuum of ward life.

Barry has come to understand that manipulation and control of staff in the community is no longer possible nor necessary. He is learning that he is the only victim of self-abuse and has nothing to gain with negative and abusive actions.

This deeper understanding comes not by punitive measures but by patient reinforcement of caring actions and the realization that he has the opportunity to make positive and beneficial choices in his life now.

Barry is beginning to consistently show the gentleness of his character as he learns to trust the staff who work for him. What is emerging in this metamorphosis is the real Barry, free of the influence and dullness of sedatives. The real Barry has a quick and subtle sense of humour, is sociable and has developed diverse and distinct interests.

Back at Granville Market, we come to the end of a two-hour walk.

"What now, Barry?" I ask.

"Suppertime," he says, grinning.

"Well, what's for supper?"

"Hamburger. Spaghetti." There's a pause and Barry looks away for a moment. He turns back to me and says, "Horse."

I burst into laughter at the thought of spaghetti and horse for dinner, but as I follow Barry's gaze I realize there is no joke here. Down the seawall into the distance bounds a huge beige dog. With the fading light, dwarfed by mountains and long unbroken stretch of inlet, it does look remarkably like a horse. I drift into the imagery of Barry as a small child, running about the farm, full of life and promise. I drift into the imagery of this wonderful and interesting man stuck for forty-three years in a way of life that denied that promise.

As he stepped onto the bus that would take him home, I was sorry to see him leave. And as I move through my own life I know I will never forget this fellow, so quick to notice and express the small joys of life.

11.

Equality Rights and Aversive Therapy[1]

Catherine L. Frazee

This chapter will consider human rights legislation in Canada and its possible application to aversive therapy methods used for the treatment of persons with a mental handicap. It is not intended as a comprehensive legal analysis, nor will it assume any position on aspects of this controversial issue that fall within the domain of experts in behavioural science. Moreover, in the absence to date of any reported human rights complaints addressing the issue of aversive treatment methods, it will be inappropriate to speculate whether in some or all circumstances, the use of aversives could be determined as a violation of the rights of persons with challenging behaviours. Rather, the thrust of this article will be to provide the lay reader with an understanding of how the fundamental principles of dignity, equality and respect for all members of society are embodied in Canadian statutory law. Building from this foundation, a practical framework will be proposed for positioning the aversives/alternatives debate within a human rights context

It is significant to note that there has historically existed no general common law principle affirming the entitlement of persons with handicaps to equality of rights.[2] It is, therefore, only through statutory enactments and amendments that the various Canadian human rights codes have guaranteed some form of protection against discrimination on the basis of handicap. Today, in each federal and provincial jurisdiction, a human rights commission or agency operates within the mandate of its particular governing statute to uphold the values of fair treatment and equality to which we, as a society, subscribe. As the precise language of each such code or act varies widely, it is beyond the scope of this paper to examine in detail the specific operation of human rights law in Canada. Instead, it should be both feasible and instructive to comment overall on the scope of human rights protections in this country and then secondly to outline some common principles of application that are of particular relevance to the rights of people with handicaps.

Scope of Protection

Two important points are fundamental to an understanding of the powerful instruments of law manifest in Canadian human rights legislation. The first of these is that this legislation is accorded a special status that gives force and vigour to the spirit as well as, and perhaps in preference to, the precise letter of the law. Judicial interpretation of human rights law is characteristically generous and responsive to the public and political will that inspired it. For example, in *Re Ontario Human Rights Commission et al. and Simpson Sears Ltd.*,[3] McIntyre J. held that the proper interpretive approach in an analysis of the provisions of the Ontario *Human Rights Code* should recognize its special nature and intent:

> There we find enunciated the broad policy of the *Code* and it is this policy which should have effect. It is not, in my view, a sound approach to say that according to established rules of construction no broader meaning can be given to the *Code* than the narrowest interpretation of the words employed. The accepted rules of construction are flexible enough to enable the court to recognize in the construction of a human rights code the special nature and purpose of the enactment (see Lamer J. in *Insurance Corp. of B.C. v. Heerspink et al.* (1982), 137 D.L.R. (3d) 219 at pp. 228-9, (1982) 2 S.C.R. 145 at pp. 157-8, 39 B.C.L.R. 145) and give to it an interpretation which will advance its broad purposes. Legislation of this type is of a special nature, not quite constitutional but

certainly more than the ordinary — and it is for the courts to seek out its purpose and give it effect.

The second important factor relevant to the scope of Canadian human rights protections flows from the fact that all such statutes in Canada are binding upon the Crown. Accordingly, while the principal thrust for federal and provincial human rights codes may be perceived as the eradication of discrimination within the private sector, the provisions of these statutes apply equally in the realm of government activity. Remedies can and have been successfully pursued from a variety of government agencies and ministries where policies or practices such as, for example, those that regulate funding allocations, are determined to have a discriminatory effect. Further, a number of human rights statutes contain a paramountcy clause comparable to subsection 46(2) of the Ontario *Human Rights Code:* "Where a provision in an Act or Regulation purports to require or authorize conduct that is a contravention of Part I, this Act applies and prevails unless the Act or Regulation specifically provides that it is to apply notwithstanding this Act."

The effect of such a provision is to ensure that when any other law is inconsistent with a human rights code, the terms of the code will prevail except in the relatively infrequent circumstance where the conflicting statute contains an express override clause relative to the human rights code. Thus, for example, if mental health legislation and/or regulations conflict with the Ontario *Human Rights Code,* the scope of the *Code* is such that it will automatically prevail.

Principles of Application

In terms of its basic operation, federal and provincial human rights legislation in Canada affords basic equality rights to specified protected classes of persons. The activities governed by anti-discrimination law generally include employment, housing and the provision of services. When a discriminatory practice is based on handicap, our various human rights codes allow a defence in circumstances where the handicap renders a person demonstrably incapable of participating in the protected activity. Such an exemption may be broadly or narrowly construed according to the precise statutory language applied. In all cases, however, the exemption itself raises an additional inquiry as to whether the discrimination can reasonably be offset by efforts to accommodate the special needs of the person with a handicap. Such accommodation, if feasible, may then be negotiated or awarded as constituting all or part of a remedy fashioned to redress the wrongs suffered by a victim of discrimination.

Within this basic framework, a consideration of five fundamental questions may assist in determining whether a human rights complaint might provide an appropriate forum for challenging aversive treatment practices:

(i) Who is protected by the *Code*?
(ii) Who is bound by the *Code*?
(iii) What are the protections afforded?
(iv) What are the limits to these protections?
(v) What are the remedies available?

The following analysis will canvas each of these questions in the context of the Ontario *Human Rights Code* — a statute that has been described as standing at the "vanguard of the new values of equality."[4] No attempt will be made to predict the possible outcome of any of the arguments presented in this section before a commission or court. Further, the reader is reminded that even subtle differences of legislative drafting may have significant bearing upon the application of any component in this analysis. For those unfamiliar with the principles and operation of human rights legislation, however, it is hoped that the brief commentary that follows may assist in shaping a new approach to one of the most controversial dilemmas of behavioural science.

(i) Who is Protected by the Code?

As noted in the introductory paragraph to this section, not *all* persons, but only those belonging to a designated "protected class" are eligible to exercise the rights defined in a human rights code. While most jurisdictions in Canada include people with a mental handicap as a protected class, actual definitions of handicap vary widely. Subsection 9(b) of the Ontario *Human Rights Code*, for example, includes within the meaning of "handicap" a broad range of physical disabilities and work-related injuries, as well as conditions of "mental retardation or impairment," learning disabilities, language dysfunctions and "mental disorders." Further, any person who is *perceived* to possess a handicap is also included within this definition. It is clear then that any person in Ontario for whom any form of behaviour modification therapy is proposed or administered can legitimately lay claim to the protections afforded to people with handicaps under the *Human Rights Code*.

This fundamental aspect of eligibility is somewhat more problematic under statutes that fail to include mental handicap as a prohibited ground for discrimination. In late 1988, the only Canadian jurisdictions in which human rights legislation does not offer such protections are Saskatchewan and Alberta. While it has not been judicially determined, it is arguable that these omissions are in conflict with the Canadian *Charter of Rights and Freedoms*, which says in section 15 that everyone is to have equal protection and equal benefit of the law without discrimination based on mental or physical disability. The argument would be that human rights legislation that fails to extend its protections to persons with mental disabilities is in violation of the *Charter* in that it denies such persons protection equal to that enjoyed by other groups who have historically been victims of discrimination. The courts could be asked to remedy this situation by reading the statute as though it included the provisions that the *Charter* requires, or alternatively declaring that the legislature be bound to resolve the inequality by amending the statute so as to include protection based on mental disability.

Any person belonging to one of the protected groups defined by a human rights code may engage the investigatory and enforcement powers of a human rights commission by filing a complaint alleging that his or her rights have been infringed. Where such a person is unable to initiate a complaint on his or her own behalf, this process can be undertaken by a parent, guardian or "next friend."

In either case, Commission staff are trained to provide advice and assistance in the formal drafting of a complaint. In addition, under subsection 31(2) of the Ontario *Code*, the Commission itself may initiate a complaint where it has reason to believe that the *Code* is being infringed. In such circumstances, the initial information supporting a complaint may come from any of a variety of sources including, for example, ad hoc action groups or committees familiar with the details and dynamics of a particular fact situation or advocacy groups with special expertise in issues arising from a complaint that may have systemic implications.

(ii) Who is Bound by the Code?

As has been noted earlier in this paper, human rights codes are binding upon not only private-sector enterprises in both consumer and commercial channels, but also public-sector agencies operating under governmental authority at any level. Thus, complaints of discrimination under a human rights code may be filed against any individual, agency, organization, institution, funding body or government ministry alleged by direct action or by policy and program to have violated the right to equal treatment of a person or persons protected by the code.

Sections 1, 2 and 4 of the Ontario *Code* identify respectively the provision of services, rental of accommodation and employment as realms of activity in which all persons have a right to participate without discrimination. A "service" under section 1 of the *Code* would be widely construed to include such activities as the provision of medical treatment or therapy, rehabilitative training or residential care in the context of either public or private clinics, hospitals and institutional facilities. Subject to the discussion in section (iii) below concerning the nature of the protections under a human rights code, it can be said that where a right exists, there is a corresponding duty incumbent upon society at large to respect and to protect that right. Thus, in the example of a person with a mental handicap receiving treatment for behavioural problems, the duty to protect that person's human rights is binding not only upon every caregiver, therapist, counsellor, case worker, physician and administrator, but also upon every agency, institution, ministry, regulating body and professional association that is either directly or indirectly contributing to the provision of treatment services.

(iii) What are the protections afforded?

Generally speaking, human rights codes articulate a right to "equal treatment ... without discrimination" for specified persons in specified contexts discussed above. By and large, codes do not provide express definitions for equal treatment or discrimination. However, Court and Board of Inquiry decisions have enunciated a number of basic principles of interpretation, two of which are particularly relevant to the subject at hand.

The first of these principles is that "intent" is not a requisite element for a finding of discrimination. In the *Simpson Sears* case cited earlier, McIntyre J., in considering the significance of intent with respect to the Ontario *Human Rights Code*, stated conclusively:

> The *Code* aims at the removal of discrimination. This is to state the obvious. Its main approach, however, is not to punish the discriminator, but rather to provide relief for the victims of discrimination. It is *the result or the effect* of the action complained of which is significant. If it does, in fact, cause discrimination; if its effect is to impose on one person or group of persons obligations, penalties, or restrictive conditions not imposed on other members of the community, it is discriminatory. (Emphasis added)

It is adverse or detrimental effects, regardless of benign or punitive motives, that meet the threshold criterion of discriminatory conduct.

Turning then to the subject of aversive therapy, an allegation that the use of such methods is a breach of a person with a mental handicap's right to equal treatment would begin with the simple claim that such treatment — outside of the therapeutic context — amounts to a kind of punishment or assault. Thus, based on a person's mental condition or handicap, rehabilitation or medical service is characterized by features that on the face of it are objectively punitive or restrictive. To use the language of human rights codes, such a provision of service could be characterized as a denial of dignity, respect and basic freedom. That the impugned treatment is motivated solely by benevolent intent and that it is ethically and professionally endorsed as being in the best interests of the client or patient is simply of no relevance at this stage in establishing a *prima facie* case of discrimination.

Another way of defining discrimination would be on the basis of the absence or presence of consent. Discrimination may not be evident in circumstances where a person who is not handicapped would certainly be free to give or withold consent, but would be evident where treatment is administered without that consent to a person identified as being mentally handicapped.

Such interpretations of equal treatment would seem to be in keeping with the prescribed liberal reading of human rights protections. Due consideration of an issue of such profound importance to the well-being and dignity of a person with a handicap should not, it seems, be foreclosed at this early stage of jurisdictional determination. Moreover, such an approach is absolutely consistent with the spirit of human rights legislation, as enunciated, for example, in the preamble to Ontario's *Code*: "It is public policy in Ontario to recognize the dignity and worth of every person and to provide for equal rights and opportunities without discrimination that is contrary to law."

As a final and succinct restatement of the principle that excludes both intent and ultimate benefit from a determination of discrimination, the following extract from the Board of Inquiry decision in *Hickling et al.*[5] appears to be directly to the point. In addressing the question of whether denial of a full Catholic education to students with developmental handicaps constituted discrimination on the basis of handicap, Board Chairman Professor Bernard Adell set out the following analysis:

> The handicapped pupil is being denied a benefit given to other pupils, on a ground prohibited by the Ontario *Human Rights Code,* 1981: mental handicap ... The fact that the pupil may as a whole be better off as a result of the denial, or that the school board's intention is to make the pupil better off, is irrelevant to whether the denial is discriminatory ... Unequal treatment which includes the requirement that a generally available benefit be foregone, and a different and possibly greater benefit accepted in its place, is not exempted from being discrimination under S. 1 either by the magnitude of the latter benefit or by the benevolence of the intent with which the generally available benefit is withheld.[6]

The second basic principle of interpreting the protections afforded by a human rights code is that equal treatment is not equivalent to identical treatment. As Professor Adell outlined in the *Hickling* decision at p. 35:

> The right to equal treatment ... really means the right to

treatment *as an equal*, or, as Ronald Dworkin has put it, the right "to be treated with the same respect and concern as anyone else."[7] Treatment as an equal sometimes means identical treatment and sometimes means different treatment. Treating everyone identically often increases existing inequalities and brings further disadvantage to those who start out disadvantaged.

Basic then to the realization of equal treatment for persons with handicaps is some recognition of existing inequalities and a corresponding effort to accommodate special needs directly attributable to the handicap. Subject, of course, to reasonable limitations outlined in the following section, this duty to accommodate is featured, at least implicitly, in the statutory human rights protections of every Canadian jurisdiction. In Ontario, following amendments designed to bring the *Code* into compliance with the *Charter*, this doctrine of accommodation is now explicitly embraced. Section 10, which deals with constructive discrimination, and section 16, which deals with direct discrimination, both impose a positive obligation to reasonably accommodate the needs of a person with a handicap.

In the same way that equal treatment is distinguished from identical treatment, a similar distinction can be made between equal treatment and "standard" treatment, where the latter is a kind of historically accepted norm or a recognized current practice. As new technologies, methods and procedures evolve, so the range of possible accommodations expands. Thus, a guarantee of equal treatment in the 1980s may translate into very different forms and levels of accommodation from those available in previous decades.

Although the recently proclaimed amendments to the Ontario *Code* have not been judicially considered, it is evident that service agencies and providers are charged with a duty to respect and to protect the human rights of their clients. In this context, it is certainly conceivable that the deployment of extra staff, additional resources and/or enhanced programs within a treatment facility would amount to equal treatment, meeting the special needs of a person with a mental handicap for care and therapy in a manner consistent with the vision of dignity and value for all citizens. Current research and new developments in the field of behavioural medicine will certainly be factored into the determination of appropriate accommodation for clients with mental handicaps.

(iv) What are the Limits to these Protections?

> In any society the rights of one will inevitably come into conflict with the rights of others. It is obvious then that all rights must be limited in the interests of preserving a social structure in which each right may receive protection without undue interference with others.[8]

In general, there are two types of limitation upon the standard of equal treatment and the corollary duty of accommodation. The first of these involves an assessment of the practical capacities of a person with a handicap; the second involves both qualitative and quantitative determinations of the extent to which accommodation is feasible.

An example of the first kind of limitation can be found in subsection 16(1) of the Ontario *Human Rights Code*, which states: "A right of a person under this Act is not infringed for the reason only that the person is incapable of performing or fulfilling the essential duties or requirements attending the exercise of the right because of handicap."

Roughly similar provisions are contained in other human rights codes, allowing for legitimate distinctions "based on handicap, to the detriment of disabled persons, where, in the circumstances, the particular handicap poses a real and provable barrier to the handicapped person's effective participation in the protected activity."[9] Such an exemption, of course recognizes that barriers are at times inherent to a handicap itself, and that some measure of inequality, as, for example, a blind person's ineligibility for a driver's permit, is unavoidable in practical terms.

Once an infringement of the *Code* has been established, a burden of proof transfers to the respondent's party to claim this particular defence, and having done so, to demonstrate that the "duties" or "requirements" in question are objectively "essential" and further that the person with a handicap is demonstrably incapable of fulfilling these requirements. In support of both prongs of this argument, a respondent will be obliged to present substantive evidence such as documentary data, expert opinion and statistical analysis; courts or boards will rigorously defer from reliance upon stereotypes, assumptions or prevailing social myths.

In the context of Ontario's subsection 16(1) and similar provisions, a respondent caregiver or facility could be expected to produce evidence in defence of aversive methods to the effect that a certain standard of behaviour is "essential" to the realization of dignity and social participation. Secondly, the argument might proceed that the complainant's particular behavioural disorder was so severe as to render him or her "incapable" of benefitting from less restrictive or intrusive procedures. It would then fall to the advocates representing this individual to rebut with evidence to the contrary, illustrating by case histories and expert testimony the effectiveness of more positive treatment options in the control or modification of similar behaviours.

Of utmost importance in a review of the limitations presented by the section 16 defence is the absolute condition applied to that defence in paragraph 16(1)(a):

> The Commission, a board of inquiry or a court shall not find a person incapable unless it is satisfied that the needs of the person cannot be accommodated without undue hardship on the person responsible for accommodating those needs, considering the cost, outside sources of funding, if any, and health and safety requirements, if any.

This explicit guarantee of equal treatment places a further burden of proof on the respondent in a human rights complaint based upon the grounds of handicap. The duty to accommodate, discussed in the preceding section, prevails over and above *any* limitation to human rights protections. In each and every *prima facie* case of discrimination involving handicap there arises an obligation to mitigate the adverse effects of discrimination in consideration of the special needs presented by the handicap, or to seek non-discriminatory alternatives to the existing discriminatory practices.

At this juncture, we encounter the second and final limit to human rights protections, expressed in codes and cited in adjudications as a limitation of reasonableness upon the duty to accommodate.

To speak of reasonableness as a limitation, although technically correct, may be somewhat misleading without reference to the context and application of this requirement. For example, under the Ontario *Human Rights Code*, barriers to equal participation will stand only to the extent that their removal imposes a burden of undue hardship. The effect of the words "undue hardship" serves more to extend than to restrict the duty, strongly and clearly stating the respondent's mandate by articulating in express terms that nothing less than rigorous effort will satisfy this statutory duty.

It is clear that the undue hardship provisions of Ontario's amended *Code* reflect some expectation of change "to the way we ... deliver services and provide accommodation, reflecting the multifaceted society we are."[10] Although guidelines for assessing what constitutes undue hardship have not yet, at the time of writing, been released by the Ontario Commission, the Code itself states clearly that only cost factors and health and safety requirements will be considered in this regard. Also evident upon a reading of the *Code* as a whole is the interpretation that the onus for demonstrating cost or risk sufficient to sustain an undue hardship defence falls entirely on the respondent making this claim.

The role that cost plays in this defence will of course vary according to the circumstances of a complaint and the resources available to a respondent. With respect to accommodation in the form of alternative therapeutic methods, a respondent treatment facility might produce evidence of prohibitive costs arising from the necessity to reduce staff/patient ratios or to upgrade caregiver skills. Generally speaking, in the case of a private facility, the ultimate determination of such an argument will require precise and accurate comparison of all such quantified costs against net assets. After this financial information has been carefully examined, a discriminatory practice would only be sanctioned if the additional cost is deemed sufficient to threaten the viability of the entire facility. Where public funding is at issue, the same basic standard would apply, albeit with different philosophical underpinnings. "Of course, governments should not be required by the courts to spend more on social programs than they are prepared to raise by taxes or borrowing. But the funds that are available cannot be withheld from some members of society in a discriminatory manner."[11]

In either circumstance, whether a service is afforded by private or public money, it will be expected to distribute costs as widely as possible, balancing the allocation of resources in accordance with a high priority upon the goal of equal treatment, and in some cases to undertake a phasing in of the desired accommodation, spreading the cost over several years.

Thus, the cost of accommodation, while not an absolute limitation upon human rights protections does provide for a reasonable balancing of competing interests in the equal treatment arena. Similarly, health and safety requirements, which a desired accommodation may be alleged to violate, will also be weighed against the magnitude of benefits thereby conferred. As with cost factors, health and safety elements also enter into the burden of proof upon the party or parties claiming the defence.

In claiming "undue hardship" by reason of health and safety requirements, a respondent service provider argues that the reduction or removal of aversive treatments would substantially increase the frequency of self injurious or aggressively violent behaviour. As with the cost defense described above, objective evidence would be required in support of such a claim. Taking into account the established human rights principle that integration and equality for handicapped persons necessarily entails some higher degree of personal risk, a commission, board or court would make an individual determination of reasonable risk in the particular circumstances.

Notwithstanding the possible application of this "dignity of risk" analysis, advocates who undertake to pioneer the human rights issues addressed in this article must at this final stage of the proceedings be prepared to counter the basic assertion of undue hardship. This will require direct evidence of proven results from positive interventions in controlling destructive behaviours as well as in realizing long-term rehabilitative gains ruled out by an aversive approach.

In the final analysis, it is likely that the undue hardship debate will be resolved in favour of whatever level of accommodation along the continuum of possibility would be most compatible with a complainant's dignity and human rights while at the same time falling below an unacceptable level of costs or risk. Presentation of evidence and ultimate findings of fact will be of utmost importance in positioning alternatives to aversive treatment as reasonable accommodation for persons with behavioural handicaps.

(v) What are the remedies available?

Award powers of human rights authorities are typically broad in scope and remedial rather than punitive in nature. For example, subsection 40(1) of the Ontario *Human Rights Code*, repeated below in its entirety, empowers a board to order compliance with the *Code* by any creative strategy, design or device, without necessary regard to precedent or convention.

> Where the board of inquiry, after a hearing finds that a right of the complainant under Part I has been infringed and that the infringement is a contravention of section 8 by a party to the proceeding, the board may, by order,
> (a) direct the party to do anything that, in the opinion of the board, the party ought to do to achieve compliance with this Act, both in respect of the complaint and in respect of future practices; and
> (b) direct the party to make restitution, including monetary compensation, for loss arising out of the infringement, and, where the infringement has been engaged in wilfully or recklessly, monetary compensation may include an award, not exceeding $10,000, for mental anguish.[12]

A positive finding of discrimination on the basis of handicap in the context of a challenge to aversive treatment practices might under paragraph 40(1)(a) result in an award involving such elements as:

- discontinuance of aversive treatments for the complainant and/or others with similar handicaps
- introduction of alternative therapy and rehabilitation methods for the complainant and/or others with similar handicaps
- staff and/or management training in alternative therapeutic techniques
- human rights training seminars for staff and/or client
- redirection or enhancement of program funding
- improved client /caregiver ratios
- scholarships or research grants

- appointment of internal liaison committees or regulating bodies
- implementation of mechanisms for ongoing service monitoring and/or progress reports to an independent body such as the Human Rights Commission
- verbal or written apologies to the parties
- press release or other publication outlining full or partial details of the award with supporting reasons

Like board orders, settlements between the parties to a complaint can take a multitude of forms. The brief list above is by no means exhaustive with respect either to awards or to settlements within this domain.

Monetary awards under paragraph 40(1)(b) for expenses incurred in the course of pursuing a complaint are of course a standard feature of human rights board awards. Compensation for "mental anguish," while arguably entirely appropriate in cases involving aversive treatments, would, however, according to paragraph 40(1)(b), require a prior finding of a willful or reckless infringement, demonstrated in the attitude and actions of a respondent /perpetrator. For this reason, it is suggested that the kinds of general awards enumerated above may prove to be a more satisfactory resolution to a human rights complaint addressing the use of aversives.

Conclusion

Protections afforded by human rights codes in 1988 represent only part — and perhaps the lesser part — of a whole that takes in all of the new and evolving equality guarantees enshrined in our Canadian *Charter of Rights and Freedoms*. Parallel to human rights law in some respects and distinctive in others, the *Charter* "guarantees that persons who live with a mental disability now have the right to live in the community and can expect all the protection and support the law can provide to enable them to exercise that right."[13] Research and exposition quite beyond the scope of this paper will inevitably provoke further avenues of thought and inspire or direct champion efforts on behalf of citizens with a mental handicap.

Quite apart from the *Charter*, however, it is the author's belief that human rights codes may afford greater and more meaningful protections to persons with mental handicaps than have thus far been explored or demonstrated. While it has not been possible to speculate on the possible outcome of a human rights complaint alleging discrimination in the application of intrusive and dehumanizing treatment methods, it does appear that the issues raised in such an allegation fall within the jurisdiction of a human rights commission. Given too that commissions will generally be guided by a philosophy that persons with a handicap have a basic right to services that meet their needs within the community, it would seem reasonable to expect a broad application of the doctrine of accommodation as a means of realizing the objective of equal rights and dignity for all persons.

It is hoped that the perspective conveyed in this article will motivate advocates and professionals to call upon human rights commissions and human rights codes in challenging any assault to the dignity of a person with a mental handicap and in bringing down all barriers to his or her fullest possible participation in society.

Notes

1. The author gratefully acknowledges the assistance of Mark Huber from the Commission's Unit for the Handicapped for his contribution of legal research. This chapter has been written solely in the author's personal capacity, and does not purport to express the views of the Human Rights Commission of Ontario.
2. M.D. Lepofsky and J.E. Bickenbach, "Equality rights and the physically handicapped," in Bayefsky, A. and Eberts, M. (Eds.). *Equality Rights and The Canadian Charter of Rights and Freedoms,* Toronto, 1985, p. 328.
3. Re Ontario Human Rights Commission et al. and Simpson Sears Ltd. (1985), 23, D.L.R. (4th) 321, McIntyre, J., p. 328.
4. Cumming, P. in *Boehm,* 1987. p. 54.
5. Decision reversed at divisional court and currently under appeal to the Supreme Court of Ontario. Reasons for reversal do not touch upon the substance of this principal, nor of that cited in the following paragraph.

6. B. Adell in *Hickling, Horbay and Legris and Lanark, Leeds and Grenville County Roman Catholic Separate School Board* (1986), Board of Inquiry, pp. 36-37.
7. Dworkin, *Taking Rights Seriously*, 1977, p. 227.
8. McIntyre, J. in *Simpson Sears*, 1985, p. 181.
9. Lepofsky and Bickenbach, ibid., pp. 329-330.
10. Quote from Raj Anand, Chief Commissioner, Ontario Human Rights Commission, to the press, 5 April 1988.
11. D. Vickers and O. Endicott, "Mental disability and equality rights," in Bayefsky, A. and Eberts, M. (Eds.). *Equality Rights and the Canadian Charter of Rights and Freedoms*, Toronto, 1985, p. 406.
12. Ontario *Human Rights Code*, (1981), c.53, s.40(1).
13. Vickers and Endicott, ibid., p. 381.

12.

A Self-Advocate's Perspective

a conversation with Pat Worth

People have many impressions of what intrusive or aversive procedures are. When you're forced to go to an institution, that's painful and intrusive. When you're forced to live in an environment that the average person could never live in, that's painful and aversive. I wonder how some of the professionals using intrusive procedures would feel if something like the cattle prod was used on them. Or if they were forced to go into a time-out room because people thought they were bad. Or if they had to walk the hallways in an institution and smell the scent of urine or have no privacy of their own in their own rooms. I think they use intrusives because the alternatives scare them. When we think of alternatives, that puts them out of a job.

I was once at a conference that presented intrusive procedures and alternatives. One of the presenters actually said that some of the people he was working with told him they "like being in restraints free from self-injurious behaviour." I was angry at that. First of all, I'm not hearing this from people with a mental handicap so I'm not going to take this professional's word for it. I believe that people can be taught to say things they don't want to say. Even scare them to death to make them say something. I know that because they scared me to death when I was in a group home. They said you stop talking about living out on your own or we'll admit you into an institution. They hung that threat over my head. One of the people from the group home was actually sent back to an institution. He said he was fed up with the group home. He didn't want to live there any more. So they said his only alternative was to move back to the institution. He went back, not of his own free will. He was thinking about running away. I don't know what stopped him. I think he should have. I took off. Others may not be as courageous because they don't have anywhere to run to. The ones who speak up learn not to because they know what they are going to get.

But when you talk about punishment, I'll give you an example. It's when a person with a mental handicap goes to a workshop and thinks she's not worth anything.

Tom used to be a pretty good friend of mine. He was my buddy in the sheltered workshop and in the group home. He decided one day that he wasn't going to do the jobs they gave him. His job was twist-tying dolls. That's what he was doing for something like seven years, longer than me. He just got bored of it and decided he was just going to sit there until they gave him something to make it worth his while being there. The supervisor told him to do his job or they were going to dock his pay. Big deal, it's not much anyway. He didn't do it so she went to the manager. The manager decided to act like the big tough guy and tried to pick him up off the chair and throw him behind the shipping door. So Tom hit him in self-defence. I call that self-defence. So Tom goes back home after they tell him to get out of the workshop, expecting the staff to take his side and advocate for him. They didn't do that at all. They didn't even believe that he hit the manager in self-defence. The management got away with it and Tom got kicked out of the group home. Tom's back home living with his mom now.

If you try to speak out for yourself and the system doesn't listen to you, there's no more advocacy. All you see are walls. That's what the group home was. If the staff didn't hear you, you'd talk to the walls. They'd think you were crazy for talking to the walls, but if they wouldn't talk to you or listen to you what are you supposed to do? If you had to live the kind of life that people in group homes had, you'd probably knock your head on tables and walls just like them.

To make workshop staff and professionals using intrusives see the alternative we have to make them listen to self-advocates more. You've got to go to the people who have been through that punishment, people with mental handicaps from institutions or from workshops. Why don't they go to them and find out how they like being in the workshop? How did they like being in an institution? Did they think it was necessary?

There is a method called "gentle teaching" that is fairly simple and should have been taught a long time ago instead of building institutions. It is an alternative that shows what happens when the walls aren't there. The alternatives to walls are communication and patience. I mean, if you don't act the way I want you to act, does that mean I have the right to haul off and hit you? You'd get pretty mad if I did. If people don't act the way some professionals want them to act, the professionals think they've got the right to use some sort of shock treatment.

Some people argue that the alternatives require too many people to work with the person who has a handicap. It only takes one person to listen. It only takes one person to advocate. It only takes one person to feel kindness. So it doesn't take all that many people. It just takes one person to start it all off. If you're living in an institution and a staff person walks by you, you want to talk to that person, but they walk by you like you're dirt or something. That hurts. What are you going to do? Are you just going to stand there and not do anything about it? Individuals with mental handicaps are defenseless people. If somebody doesn't talk to them, they hit their heads, because that's the way they get a reaction. I'll bet you that none of this would have gone this far if positive alternatives would have been in focus in the first place instead of building institutions. Society builds walls when it builds institutions. It builds walls to keep people with handicaps in and away from society. But if it can build walls, it can tear them down.

And there are other things like being forced to earn tokens, food and outings that don't seem harmful but they are still intrusive because they're still a punishment. I shouldn't have to earn the right to have food. Why should I have to behave to get that? You're talking about behaving and you're talking about the way they want you to behave. That kind of treatment is a power trip. People use these simple little power trips to say: "If you don't behave you don't get these candies today." That's what they say to people in jail: "If you don't behave you won't get your bread and water." This is even worse because people with a mental handicap in institutions haven't committed a crime. Nobody's telling staff that if they don't behave, they shouldn't be working there. They're a risk to people in institutions. The staff consider people with a mental handicap a risk to society, but actually the staff are a risk to us. Just by saying if you don't behave you don't get this food — we'll eventually starve to death. We're innocent inmates in institutions.

In my job, I visit institutions and help people there. Although I know what's going on there, people are too scared to talk about it. Not too long ago I went to a meeting at a regional centre. At the group meeting, there was this one very scared person sitting there with a black eye. I asked him, "Who did this to you?" He looked at me as if he was going to say something, then I said, "Was it a staff person?" And he absolutely froze. He was scared to death.

So far, I haven't been able to get close enough to these people to hear their stories. Why should they talk to me anyway? I get to go home at night, I don't have to stay there. They know if they talk to me, chances are they'll get in a lot of trouble. The punishment gets worse if you tell somebody else about it. It's not that they don't trust me, the problem is I'm never left alone with them. There is a staff person there all the time.

One person dared. He didn't talk about the procedures used against him, although you could see it. His name is James. He talked about missing his mom and his dad — he's been there for seventeen years. He said he's about thirty-five. James wants to get out. He knows the terrible things the system is doing to him. A lot of people with mental handicaps don't know. He's scared every day of his life. And I know he's in trouble because he's losing weight. He's dying. He's in a wheelchair so he can't exactly walk out. He's a person who they said was low functioning and had a learning problem. But he can talk the same way I can. Do I have a learning problem?

In fact, the silent treatment is another intrusive procedure. One of the staff people (this was before she found out I was involved with People First) was sitting with me during coffee break and she was telling me a story about a person with a handicap who had attacked her in the institution. She walked by him on her way to the office and he was upset about something and wanted to talk to her but she didn't have time. So he just walked into the office, grabbed her by the arm and he pushed her into the corner. She hurt her back. Apparently, they sent this person off to be cattle prodded. You're not talking about someone who was banging his head or abusing himself. You're talking about somebody who pushed a staff person. Her way of pushing him back was giving him shock treatment.

He pushed her because she ignored him. When I go to the institution the first thing I see is people who have been labelled retarded walking all around the place with nothing to do. People are just walking the halls like zombies.

If I were one of those people who couldn't speak but was suffering I would be saying, "Help me, I'm dying." That's all that should be needed to say. When I first met James, from the first minute he saw me, he knew I was not a staff person. That was the first thing he said to me just before a staff person came in. It's so hard to build up their trust. I've only been on this job for two years and although I've gained some trust I understand why others don't trust me. They've been treated like dirt by everyone they've come into contact with. Why should they trust me? I'm going to continue building their trust, I think I can. But it's going to take a long time. That's the damage the system has done.

Unfortunately, I don't think many people who are institutionalized are aware that it's not done to everyone. I think they really believe they have to have it done to them. They probably think that a lot of it's done to people in the community. They don't realize that only they are being treated this way.

And the government isn't helping matters. The Ontario Research Council spent $90,000 on improving the cattle prod. I would have spent that money building accessible homes. The minister made a big announcement about the multi-year plan to reduce the number of institutions and then he turns around and gives the Research Council $90,000 to develop another stinking new prod. I call it the people prod. What a backwards government.

Those people are going to die before they can get out if this keeps up. It's going to be too late to build homes for them. They're going to be dead. Never mind what it means when they come out — will they go into boarding homes or group homes that continue using those treatments? They're going to build their own institutions in the community — make the whole community an institution.

Of course we now have the *Charter*. But what's in the Canadian *Charter of Rights and Freedoms* is nice words. It sort of reminds me of the American Declaration of Independence. They read out these fancy words in black and white and decided what independence meant. But then they still went around killing people. The *Charter of Rights* you know, the words are nice, but the words are just on paper. Where does the paper go? The paper goes in the garbage.

What we need is a strategy. If just one person goes to the minister, he doesn't have to listen to that person. If two people go, he may listen. If three people go, there's a better chance. If an organization goes, what chance does the minister have? He can't walk away. If the organizations around here that support people with a mental handicap would just stop taking single stands and put some joint action behind those stands, we would have positive results. Why should you have to make an appointment to see someone like the minister? If an organization decides to go into his office, I don't think he would stop you. He fights force with force to keep us away. Organizations have got to fight force with force to tear the walls down. People like that are the reason why the walls are still standing. It is people like us who have taken the stand against the walls. You've got to do something to tear them down.

People First is taking action against the multi-year plan in Ontario because we have to be involved. We've got to have our say in that. The multi-year plan is supposed to be a plan designed by the ministry to close institutions, I think, within twenty-five years. I think that's too long. They'll all be dead by then.

Time is important in another sense. I think time is something that we have to give to other people. But in the institution, all they have time for is walking the hallway. That's not time actually: that's death. They're waiting to die. Some professionals have time to inflict unnecessary pain but they don't have time to listen. They are the jury: they sentence them. In a court of law, when criminals are convicted they are sentenced and the jury decides what the punishment will be. So I believe that in cases where people have a mental handicap, society is the jury and they're saying too bad, your sentence is a life in an institution or a group home. Their only crime is that they have some kind of handicap. If that's true, why aren't some professionals locked up? Their handicap is that they have a closed mind. They've been getting away free.

And it's not just doctors and professionals who have to change, it's ordinary citizens. If they've never lived that kind of life and they don't know what it's like, they should darn well listen to experienced people like Peter Park who lived in an institution for eighteen years. He speaks about the institutional life and everything he says is fact. When he goes out to the public though, they're always questioning whether this is true or not and if they have doubts, then that's the time for hearing them. That's the time when they should be pushing the government to go inside institutions. If they want to see it for themselves I think that's great, that erases doubt. The community hasn't pushed the government hard enough yet to open the doors.

And I don't think ordinary citizens know anything about institutions and intrusive procedures yet. I think they believe that institutions are a good place. I think that's what a lot of parents think. You know these days parents are even told by doctors before-hand if their child will be born retarded. The doctor's word is as good as gold, doctors can't be wrong. It's hard for a mother to accept that a doctor is wrong. A lot of mothers over the years have been putting their sons and daughters in institutions.

It takes a lot of listening because there are horrible stories, they're unbelievable stories. But even if you have any doubt, it is reason enough to push the government.

Another challenge is convincing parents. It's very difficult but you have to take their blindfolds off. I've actually done it, I've actually convinced some parents that that kind of treatment is not necessary because I've talked about my job and my life. A lot of people think that people with a mental handicap can't talk to people in the community and here I am in the community talking to people. The alternative is simply listening. I think to teach people like that, you have to rebound against what they're going to say. You take away their argument and you're really powerful with your own argument. I would say to a parent like that, look at the results in my friend when someone listened. My friend didn't bang his head any more. My friend stopped hitting himself.

Actually Peter once told me that there was a person with a mental handicap he knew who would bang himself all the time and he wouldn't stop. He saw this staff person walk by and ignore him, so Peter came over, held his hands in a gentle way, and said, "What did you want to say?" He told him plain and simple. I would still say to the parent, the alternative is to have feelings and to listen and care. Just listen to that person and he or she will tell you what they want.

I know it's hard for one staff person to care for five or six people who are banging their heads. So then it's time to have advocates. Each person should have an advocate. If one staff person is trying to listen to six people all at one time, then there's no way he or she can do it. The part that makes People First members so vulnerable in institutions, group homes or sheltered workshops is that they're put away in a place where they can't be heard. They have nobody speaking out for them. One good staff person can't walk around to 923 people and listen to all their problems. But I can't see any reason why you can't have 923 advocates walking around listening to all their problems. I'm talking about volunteer advocates — people free from the system. It all goes back to answering how you get the community involved in institutions — by forcing the government to open the doors. Step two — after you get the doors open, you let them inside to see what goes on. It automatically becomes clear why you should advocate. I'm a self-advocate and I also advocate for people with mental handicaps in general. But I can't be there to stop the punishments all the time. I'm not there all the time to say — Aw no, this is wrong. I can't do it all by myself. I'm only one person. Having an advocate there, at least a lot of the time, will allow him or her to become a part of the person's life, a real friend, who could become the person's closest friend. An advocate is somebody who goes inside the walls and listens to a person behind those walls even though the walls are there. The advocate should be right there with the person who has a mental handicap.

There are other ways to help knock down those walls. I'm going to suggest to people with all good intentions, stop using paperwork. It doesn't work. Paperwork amounts to filing things away. Fine, let's do that, but we have to go beyond there. The paperwork isn't the mouth. The mouth is what creates the action. Start going into colleges and universities, start hitting the politicians — you can push them to support you.

Peter Park talks to everyone about his experiences to educate them. Barry Smith talks about his experiences at the Edgar Institution and the time-out room. I don't know what his crime was — probably being a nice guy. A lot of people, and not just People First members, will tell you about their experiences at conferences because that's really the only time that they get a chance to speak up. I can't get around to all of them. There are too many. They'll say, when I was in the institution, I had nothing to do. I was walking the hallway because there was nothing better to do. When I was in the institution, they used to put me into this dark room because I got into too many fights. Or I was sterilized, which up until the *Eve* case was general practice in institutions.

I tell people about my life too. I was in a group home that is like a mini-institution. There were thirty-five people living in that home. You had to share your room with five other people, line up for your meals. I wasn't very big then, I was only about 55 kilos but they had me on diet foods. You see, I am more than 183 cm. tall and now weigh about 102 kilos. It seems the staff are only concerned about getting the job done. They get paid whether we eat, sleep or whatever. You're talking about people in the system who are well trained not to care. If they put slop on the table and you're faced with either eating it or not eating it and starving, what are you going to do? Where I was living, the staff did the cooking. But I should be fair, I think there are some staff who care, but they are maybe about two or three in a dozen. What are those two or three people going to do? Most of them are too afraid to talk because they'll lose their jobs if they show some sign of care and the good ones leave the system all the time. They can't stand looking at the treatment. If you're a good-hearted person who really shows feelings towards people who are very vulnerable, how can you go into a sheltered workshop and watch them sit there twist-tying dolls or packaging diapers? How can you go into a group home and be caring while they share their room with five other people? Or to be lectured by staff when you say you want to move out? Or to be threatened that we'll send you to an institution if you don't stop talking bad about this place. How can you stand watching that if you really care?

And staff get tired of hearing complaints. The people don't want to eat steamed food. They want to eat real food. All they hear is the ministry says this, the ministry says that. All staff do is come out with excuses why they can't get an oven in for Pete's sake. What bothers me is that institutions have a lot of money. One institution's budget is $65,000,000 per year. What are they using it on? Certainly not on recreation. They have nothing to do there during the day. They're just using that money on a cafeteria full of steamed food and the time-out room, wards after wards after wards after wards. They're not using it on building privacy. They're using it on making people feel angry when they have to line up to go to the washroom, making them feel angry because they have no privacy, making them scream out because they have nothing else to do, making them die because they can't survive.

It's the attitude that does it, and the way people think. The first institution was built on attitude.

It's time to change those attitudes. If I were a staff person and someone was being self-abusive, I would ask if that person wanted to be touched. She's hitting herself to be touched. Nobody else touches people who are forced to live in these places. So what's wrong with coming along and holding their hands with care and saying, "Did you want to say something?"; just listening to what they had to say.

If I were a staff person in an institution and someone was trying to harm me, I would put up my arms like I'm almost surrendering and say, "Did I do something wrong?" If you struggle enough, one of you is going to give in. But during the struggle you're going to be communicating. That person's not going to hurt you because during that time you're going to be listening to that person, because you're going to be touching that person.

And if the person was throwing objects across the room, I'd have the same attitude. Throwing chairs across the room is not harming me. Sometimes at night when I'm really angry I pick up my pillow and I throw it across the room. The message is: they want to get the hell out. I say, I'm willing to listen.

At one institution, I have this friend whose name is Derek. Derek's an interesting guy. Sometimes he's nice, sometimes he can be hard to get along with, sometimes he's temperamental. Sometimes six people are needed to hold him down. They're not doing it with love, they're doing it as their job. But if those six people were hugging him to make him feel secure, that would be the difference.

These restraining procedures or other intrusives are not being used on people like you who haven't been labelled. I was speaking at a conference once and I told everyone in the room, if you could all close your eyes for five minutes and imagine what it would be like for you without community living and you were all living in an institution or a group home and it was so crowded you felt like screaming, no privacy, no job, nothing, just institutional behaviour, you would wake up and say I have the right to be treated as an equal. I have the right to get out and make my own life. I have the right to get the support that I need. If everybody in the world was living in an institution, you'd all die one by one. This whole world would be nothing but a holocaust. That's how it's violating their rights. It's because you're saying to people who have been labelled, you've got to die.

A lot of people ask me, what would be the final victory for all people with a mental handicap? It's when the last wall comes tumbling down and we all get to go home, raising our hands and head in victory saying: "We've got a home now. We're going home." And there will actually be a home there. Just a natural way of life without all the things that were in the institutions. In my lifetime, I want to see that day. I'm going to do everything to make sure I see it. I saw it for me, I saw it for Peter, I want to see it for everyone until the last wall comes down, then I want to lead the march to freedom. I have this wild dream where I imagine the last wall coming down and all people with a mental handicap in the province marching with a flag of freedom to the provincial government buildings in Ontario and saying to the Premier, "Too bad you lost." Then, they'd all go home and have a real supper.

About the Contributors

Mary E. Collins is Kelly's sister and advocate.

Bill Downer is Executive Director of the Strathroy and District Association for Community Living, Ontario.

Dot Ewen is Executive Director of the Vancouver Neurological Centre.

Catherine L. Frazee is a Commissioner with the Ontario Human Rights Commission.

Dorothy M. Griffiths is Director of York Behaviour Management Services in Richmond Hill, Ontario.

Jill Leach is based in Vancouver and has worked in a number of capacities with people who have a mental handicap, ensuring they have personal support networks when they move into the community. She is currently monitoring group homes and vocational programs in British Columbia.

Doug Logan is Executive Director of the Victoria County Association for Community Living.

S. Dulcie McCallum is a Victoria-based lawyer and the Government Affairs Consultant for the CACL.

Peter Park is Project Officer for the National People First Project, a self-advocacy movement, and Past-President of People First of Ontario.

Margaret Price is the mother of Jeremy.

Marcia H. Rioux is Director of The G. Allan Roeher Institute in Toronto, Ontario.

Carole Sinclair is the Director of Treatment Services at the Dellcrest Children's Centre in Toronto and Co-Chair of the Ethics Committee of the Canadian Psychological Association.

Tim Stainton is a doctoral student at the London School of Economics in social policy and mental handicap. He was formerly Manager of Policy and Programs for the Ontario Association for Community Living.

Yves Talbot, M.D. is the Family Practitioner in Chief at Mount Sinai Hospital in Toronto and Associate Professor at the University of Toronto in the Department of Family and Community Medicine.

Brian Weagant is Staff Counsel for the Canadian Foundation for Children and the Law (Justice for Children) in Toronto.

Pat Worth is President and co-founder of the People First Project of Ontario.